

# **Valuing Inclusive Play: Researching with Disabled Children**

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Thesis submitted in partial fulfilment of the requirements for the  
Master of Research

October 2018



## Statement of Originality

*This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.*

A handwritten signature in black ink, appearing to read 'Ebony Appel', with a stylized, cursive script.

(Signed) Ebony Appel

Date: 19/10/2018



# Research Summary

Children with disabilities do not have the same opportunities to engage in meaningful play, social interaction, and peer-based learning as children without disabilities. Understanding the spaces in which this disadvantage plays out is key to alleviating the pressure felt disproportionately throughout our communities. Public playspaces are one such environment. It is argued that through the thoughtful creation of public playspaces using Universal Design principles, we can provide these children with the opportunity to experience that which they have historically been denied - their right to play.

This research project evaluates the experiences of play which four children between the ages of six and twelve with experiences of disability have, in a universally designed playspace in Ryde, NSW. The project addresses the following research questions:

1. In what ways can children's experience of play be captured using participatory methods,
2. What are children's experience of inclusive play spaces?
3. What have Local and State Government responses been to the challenges which children with disabilities face when engaging in play?

By answering these questions, the research also develops and trials innovative research methods for conducting research with (Matthews & Limb, 1999) children who have disabilities. Research on the experiences of children with disabilities is recognised as a large and politically charged gap in academic research. This, in-part, is due to a reluctance of the research community to engage with vulnerable groups owing to anxiety for their ethical treatment. The rationale of these new research methods is to challenge this anxiety and bridge the gap in research by distancing itself from traditional research approaches which investigate child experiences by-proxy. This research instead elevates the child research participants to the level of 'co-researchers', allowing for their ideas, experiences, and authority to be recognised.



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## **Preface and Acknowledgements**

The research reported in this thesis has been completed as part of my Master of Research program at Macquarie University. The MRes program offers students research training in preparation for doctoral studies and encourages students to undertake research that leads to a PhD proposal. While at some levels this is a rather 'academic' orientation, assuming that the PhD is the ultimate goal rather than the research project itself having an intrinsic contribution to make, the opportunity has taken me to places I would not have previously imagined. The freedom to pursue research questions that matter deeply to me without the immediate pressure of producing outcomes that change the world, and to develop the skills, knowledge and understanding that might lay suitable foundations for doing a larger piece of research that actually gets things right has been awesome in every sense of that word.

I would like to thank Rebecca Ho and Touched by Olivia Foundation for their enthusiastic contribution and guidance during this journey; my MRes supervisor Professor Richard Howitt for his unwavering support and encouragement when it was needed most; and I am especially grateful to my co-researchers and their families for letting me glimpse into their complex, challenging, and rewarding lives, and without whom this work would have not been possible.



# Chapter 1: Introduction

Public playgrounds support the healthy and happy growth of children. They are important spaces in which children learn and grow through social interactions and physical challenges. Despite the recognition of the value of public playspaces in Australian cities by researchers and city planners, and the commitment of considerable public funding to their development and maintenance, children with disabilities still face considerable barriers to accessing, using and benefitting from public playspaces in many places. Their access to opportunities to play are significantly limited in contrast to non-disabled children causing them disadvantages such as delays in social, emotional, cognitive, and physical development (Milteer & Ginsburg, 2012).

In New South Wales, a recent Government policy change marks a significant transformation in the landscapes of inclusive play in that state:

*Playgrounds and play spaces across NSW will need to meet a new standard of design by catering for all people, including disabled and able-bodied children and their carers.*

*Minister for Planning and Housing, Anthony Roberts, said the NSW Government wanted to ensure everyone was able to enjoy these spaces safely and inclusively and would provide an injection of funding for councils to retro-fit all existing parks within five years.*

*"I want all playgrounds in NSW to be reviewed as part of an in-depth audit that will see them assessed and rated against universal design principles," Mr Roberts said (Roberts, 2017).*

The new policy includes a public consultation process, development on new guidelines, new inclusive design benchmarks for all public playgrounds in NSW and new resources to support local government to implement the guidelines. It draws heavily on Universal Design (UD) principles with the aim of creating functional spaces for all users (Roberts, 2017). Successful delivery on this new policy will, of course, look different in different places and for different children. The success of a playspace sits in its capacity to provide access to "the basic human right to play with others" (NSW Commissioner of Open Space and Parklands, Fiona Morrison, quoted in Ministerial Media Release, 08.11.17, Roberts 2017).

This thesis reports research which explores the experience of children with disabilities using existing inclusive playspaces in order to better understand what success in this public domain might look like, how it might feel for children and their networks of love, care and support, and what it might mean for local government, disability support advocates and the children and their families. The research was undertaken in the City of Ryde, in Sydney's northern suburbs, where Ryde City Council has already supported improved access to and useability of playspaces for disabled children in their community. In 2013, Ryde Council established the inclusive playspace, Livvi's Place, in Yamble Reserve (see <https://www.ryde.nsw.gov.au/Recreation/Parks-and-Sportsgrounds/Find-a-Park-or-Sportsground/Yamble-Reserve>) in collaboration with Touched by Olivia Foundation (TBO). Touched by Olivia Foundation is an inclusive play advocacy group established by John and Justine Perkins, residents of Ryde, to honour the memory of their daughter Olivia. This playspace was designed with the principles of Universal Design (UD) and the community's diverse population in mind, to ensure that people of all abilities are given opportunities to play. It won the 2013 NSW Minister for Planning & Infrastructures Sydney Greenspace Award and the Premier's People's Choice Award in the NSW Landscape Architecture Awards. The Award Citation read in part:

*The aim was to create a fully inclusive community space where able bodied children would be able to play happily alongside their disabled peers, and where carers were adequately provided for. Following significant funding from the NSW Government Metropolitan Greenspace program, the design and engagement process, that has proven so fruitful in other jurisdictions, successfully instilled enough enthusiasm and commitment from many other suppliers, and corporate sponsors, that the project's vision could be realised to the quality that it is today [<https://architectureau.com/articles/2013-nsw-landscape-architecture-awards/> accessed 07.10.2018].*

## The research questions

To understand the experiences of play for disabled children in the City of Ryde, the research addresses the following questions:

1. In what ways can children's experience of play be captured using participatory methods,
2. What are children's experience of inclusive play spaces?

3. What have Local and State Government responses been to the challenges which children with disabilities face when engaging in play?

Using the Yamble Reserve Livvi's Place as a case study location, the research aimed to work with children with disability to educate policy makers, young disabled people, and their support networks on providing equitable access to opportunities to play. Touched By Olivia Foundation supported the research, assisting with participant recruitment and directing the researcher towards a number of key stakeholders and networks. As the research preparation proceeded, it became clear that there is no single set of established research methods suitable for working with this diverse group in ways which value the voice of the child. A review of the literature (Chapter 3) recognised that it would be necessary to work at the intersection of two broad research fields: Universal Design and Children's Disability Studies and to develop a research design and methodology appropriate to the specific context in which I was working. Consequently, it became clear during the project that the research would also aim to strengthen the existing knowledge on working with children with disabilities by reflecting carefully and critically on the way it was developing and trialling innovative research methods and practices.

Existing critical discussion on the success of UD emphasises the importance of its effective implementation of its principles in areas such as spatial design. There is general consensus on this with people such as Beckett, Holt, and Moore (2012); Jones (2014); and Torrens (2000) outlining trialled techniques of 'designing with' the user group to create more functional spaces. This evaluation is limited, however, as the positive impact which UD has on these user groups is rarely considered, but taken-for-granted. Research on whether UD is an effective way to create considerate spaces which act to alleviate the pressures of disability on disabled children is, subsequently, engaged with even less. Those who do, prioritise the evaluative and interpretive skills of adults, whether they be parents, carers, or teachers, over those of the children themselves. Taking into account the well-established consideration of the 'child's voice' present in children's geography studies, this research provides three fundamental contributions to this area of study:

First, this project seeks to evaluate this taken-for-granted assumption that UD is sufficient to create more accessible spaces and therefore better social inclusion of children who are spatially marginalised by disability. Second, the research proposes that prioritising children's

evaluations and experiences is methodologically central to making this evaluation worthwhile and make the invisibility of social exclusion from play more visible. And thirdly, this research seeks to reflect trust and confidence in the value of these children's voices by exploring ethically sound research methods designed for researching with children who have experiences of disability.

Communities and their local government councils have a responsibility to engage those who are at a disadvantage in terms of access and participation. This is especially so when considering children, our future community leaders. Fair and equitable access to opportunities to play is therefore an important way to ensure that social engagement is fair and reaches across the entire community. Having access to an environment which caters to a variety of needs and abilities is essential to the success of providing every child with the opportunity to grow. While these steps forward suggest that Ryde Council is at the forefront of policy improvement, the reality is much more ambiguous as inclusive access to play is influenced not only by design, but also by policy, user behaviour, as well as social and institutional discourses.

## **The Invisibility of Disabled Children**

There remains a dramatic underrepresentation of the experiences of children who have disabilities in academic research. This is reflective of the 'Othering' which these children also experience in their day-to-day lives (O. Jones, 2008; Pyer, Horton, Tucker, Ryan, & Kraftl, 2010). Reasons cited for this research gap by Jones (2008) and Pyer et al. (2010) include the anxiety of the ethical treatment of disabled children, and established research methods for conducting research with children who have disabilities which focus on the input of the caregivers and not the children with experiences of disability.

Abebe and Bessell (2014) conclude that disabled children are often avoided in the research context as many researchers are unsure of how to best approach them. Fearing over-complicated ethical constraints and challenges, most research on the experiences of children with disabilities only consult with their parents, carers or teachers (Ali, et al., 2001:951; Benzon, 2010). This results in a limited understanding of children with disabilities as their



experiences are understood through an third-party interpretive manner, rather than directly from the source.

The adverse consequence of limited academic coverage of intersectionalities, like 'disability', 'children', and 'play' is the consequent invisibility in areas such as public awareness, policy, and Government funding. Consequently, despite the delivery of inclusive public spaces generally, and inclusive playspaces in particular, being a political and policy priority in NSW in 2018, there is still a research deficit which needs filling to better inform these policies as the utilization and impact of inclusive spaces is not well-researched or understood.

Advocacy and disability support groups, including TBO, support research on the impact of inclusive design on children with disabilities. There is, however, still a great deal of work to be done to better inform our communities and policy makers.

## **Impacting Regulatory Frameworks**

Ryde Council is widely recognised as a leader in local government support for children with disabilities because of its leadership in developing the Yamble Reserve Livvi's Place. The recently developed Ryde Council's Disability Inclusion Action Plan (DIAP) meets the NSW Government's request for local council action to standardise their approach to disability inclusion across communities. Community consultation to develop the Ryde Council DIAP highlighted the need for more liveable cities (Ryde City Council, 2017: 21). Facilities required included accessible paths, bathrooms, public transport, as well as parks and playgrounds. In response to this consultation, a specific action to 'review the design of parks and playgrounds to propose that they cater to a range of age groups and allow for multi-generational enjoyment' was included. One year after creating the Ryde DIAP, however, Ryde Council reported that this fundamental action, which will underpin remediation of existing playspaces that fall short of the required standard had "still not been done" (Email response from Manager of Parks, Ryde Council). In addition to the Ryde DIAP, the City of Ryde has in place several other strategic frameworks to support the rights of the disabled person. These include the City of Ryde Access and Equity Policy (2009), the City of Ryde Community Grants Policy (2014), the City of Ryde Engagement Policy (2008), and the City of Ryde Engagement Framework (2008).

Despite these strategic commitments to engage with the needs of the disabled children to have access to play, and the installation of a leading inclusively designed playspace (Livvi's place in 2013), Ryde's playgrounds more broadly do not meet the set criteria of even their own Council when it comes to accessibility and functionality. Out of seventy-five playgrounds and parks in the Ryde Council region, only one meets the guidelines set out by the local council level frameworks and guidelines of UD, which will inform the new state-wide guidelines.

## **Thesis Structure**

This thesis reports on research that has aimed to make a modest contribution to filling the gap in research by working directly with a small number of children with disabilities to better understand their experience of inclusive playspaces, and to better understand the context in which change towards better outcomes that allow children appropriate access to this fundamental human development opportunity. Chapter 2 introduces the current context of play for children with disabilities in NSW. It reviews developing guidelines, LGA 'best practice approaches', academic literature, and insights from stakeholder interviews where key individuals were invited to reflect upon the experience of play for disabled children and their support networks. As indicated above, Chapter 3 reviews the literature from fields of study which influence the context for inclusive play for children with disabilities in NSW. An habitually unrecognised area of study, inclusive play for children with disabilities, or 'inclusive play', straddles the intersection of literature of Universal Design, Children's Geographies, and Disability Studies. Chapter 4 discusses how the research responded to the ethical and methodological challenges arising from working with children with disabilities. It outlines the methodological approach adopted and the methods developed and applied to collect the research data. Chapter 5 introduces the study location. It provides summary statistics about the City of Ryde and introduces the Yamble Reserve Livvi's Place playspace. In Chapter 6, the individual child co-researchers who contributed to this research are introduced and their experiences in Livvi's place are considered in detail. Chapter 7 discusses the research findings and applies these to the task of answering the research questions. In Chapter 8, some methodological lessons arising from the research are discussed and conclusions are drawn, including some critical reflections on future research priorities.

## Chapter 2: Rethinking Disability, Play, and Inclusion: Framing the Issues in NSW

The opportunity for children with disabilities to play in public playspaces is constrained by public policies and regulations that have not required a minimum standard that meets the needs of many children. This chapter reviews the current context of play for children with disabilities in NSW. It reviews existing and emerging trends in regulatory guidelines, 'best practice approaches' in local government, academic literature, and insights from key individuals who reflected on their experience in supporting, advocating and advancing inclusive play for disabled children in interviews for this research. There is currently significant pressure for change, reflected in the new NSW Guidelines referred to in Chapter 1, but progress towards successful implementation is uneven, even where it is supported.

### Commonwealth Context

The Australian Parliament passed a national *Disability Discrimination Act* in 1992, which established the role of Disability Discrimination Commissioner in the Human Rights and Equal Opportunity Commission. The first Disability Discrimination Commissioner (1993-1997), Elizabeth Hastings noted that:

*disabled people didn't want sympathy, let alone pity or charity; they wanted their human rights (Henningham, 2014)*

According to the Australian Human Rights Commission, which oversees the legislation, the *Disability Discrimination Act 1992* intends to:

*eliminate discrimination against people with disabilities  
promote community acceptance of the principle that people with disabilities have the same fundamental rights as all members of the community, and  
ensure as far as practicable that people with disabilities have the same rights to equality before the law as other people in the community  
(<https://www.humanrights.gov.au/our-work/legal/legislation>).*

Australia ratified the United Nations *Convention in the Rights of Disabled Persons 1975* in 2008. In 2011, the Council of Australian Governments committed to developing and implementing a National Disability Strategy (Council of Australian Governments (COAG),

2011). In responding to that commitment, Australian governments have both produced and struggled to understand dramatic changes in the way that disability is understood and responded to socially, politically and legally.

Those changes have most notably focused on the increasing presence of a social model of disability in policies, which promotes engagement of communities in the welfare of the socially marginalised. Policy documents such as the National Disability Research and Development Agenda (2011) outline the commitment of Federal and State Governments to spend resources (\$10 million for research between 2011-2016) on pushing this new agenda.

## **Inclusive Play in NSW**

NSW endorsed the National Disability Strategy in 2011, and the NSW Government has made significant commitments towards alleviating some of the pressures which children with disabilities experience in playspaces. The policy initiative referred to in Chapter 1 endeavours to shift the default position for public playspaces to develop policies and guidelines which will identify a best-practice model for disability inclusion, and designing playgrounds which are accessible and usable for all. The New South Wales Government's 2018 inclusive playspace guidelines are discussed below and represent one of the changes which brings the topic of disability inclusion to the forefront of conversation, targeted toward the physical spaces in which they are enacted. In the context of inclusive play, public parks and playgrounds are a space of particular interest.

## **'Everyone Can Play' Guidelines**

The 'Everyone Can Play in NSW' guidelines (NSW Department of Planning and Environment, 2018) is a five-year strategy which looks holistically at the accessibility of public parks and playgrounds in NSW. The strategy consists of the development of the inclusive design guidelines through stakeholder and community consultation. It prioritises user-contribution to the development of space and in particular makes emphasis of the importance of hearing the input of the children who will use the spaces. The program includes several checklists which help playspace users and developers to identify design features which are inclusive, or which are often overlooked as problem areas.

The guidelines are aimed to create high-standards of community inclusivity through the engagement with the principles of Universal Design. Described as a “best practice toolkit for local governments, community leaders, landscape architects – or even passionate local residents – to use as a reference guide for creating world-class playspaces that are designed to be inclusive of everyone in the community” (NSW Department of Planning and Environment, 2018, p. 3), the program pushes for better engagement under the three triggering questions:

- Can I get there?
- Can I stay?
- Can I play?

The accompanying check-lists (Figure 2.1) provide practical assistance to help with the evaluation of playspaces based on catering to these three requirements. Ensuring that all playspaces meet these requirements guarantees that playgrounds remain a viable community asset, for the whole community, for generations to come. The inclusion of these checklists was in direct response from local councils who expressed their concern for putting the concepts of UD into practice, requesting a clear and concise explanation of how UD can be recognised and engaged with in everyday design.

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**Figure 1: Extract from the ‘Everyone Can Play’ checklist (DOPE 2018: 53-54)**

The NSW Government’s commitment to implementing this strategy ensures that there will be a consistent vision, state wide, on the challenges faced by playground users, strategies to

address these challenges, standards to meet and exceed, as well as evaluation methods to ensure the standards are maintained.

The importance of incorporating these UD principles into universal guidelines is to ensure that a clear message of inclusion is sent. This program is indicative of the work which has been done by TBO to link key stakeholders on the topic of inclusively designed playspaces. TBO's executive officer, Rebecca Ho, shares these views and suggests that the NSW guidelines are "an instrument of change". It will enable a comparative approach to improving the environments of play, providing innovative and community endorsed ideas to make play accessible for all. Meaning, the challenge of inclusive play is no longer to identify *what* an inclusive space looks like, but is now one step closer and focused on *how* to develop one.

## **Disability Inclusion Action Plans**

The NSW State Government also ensures the continued engagement with their community members who have experiences of disability by regulating the design and implementation of 'Disability Inclusion Action Plans' (DIAPs). The DIAP is a document which identifies the systemic and attitudinal barriers which people with a disability face in a particular community or Government department, for the purpose of developing processes to address these barriers. It is identified to be an effective "way in which Governments, public authorities, and organisations can reduce and remove barriers for people with a disability and foster a more accessible and inclusive community" (NSW Government, 2015). It also follows in line with the social model of disability, and leans into the academic knowledge in the field of disability studies.

The four key areas which the NSW DIAP aims to support are:

1. Developing positive community attitudes and behaviours
2. Creating liveable communities
3. Supporting access to meaningful employment
4. Improving access to mainstream services through better systems and processes

Especially relevant to the current state of play for children with a disability in NSW is the processes in place to create liveable communities. This target ensures that people with disabilities are able to participate in all aspects of community life through initiatives in spatial

design like the upgrade of public infrastructure to improve access. These measures outlined in the NSW DIAP are integral to the support of children with disabilities' ability to engage meaningfully in their community. The more our physical environment is inviting and accessible to people with disabilities, the more opportunities to develop positive community attitudes and behaviours will arise.

While all NSW Government departments, Local Councils, and public authorities (e.g. the NDIA) are required to develop and implement a DIAP, organisations and private businesses are not held to these same expectations. The DIAP is instead only advertised as a *best-practice* implementation of disability engagement. The result of this is a lack of engagement at the community level, where these systemic barriers and uninformed attitudes transform into experiences of exclusion for people with disabilities. The arising challenge which has unfolded from this is how do we engage the community at the individual level to participate in NSW's progressive model for disability inclusion.

## **Inclusive Play Australia-Wide**

The Commonwealth Government's engagement with the needs of young children with disabilities' access to equitable play opportunities has also seen a dramatic shift in recent years following the rollout of the NDIS and the increasing influence of research institutes, advocacy groups, and peak bodies. Engagement with groups such as Children and Young people with Disabilities Australia, People with Disabilities Australia, and the Centre for Universal Design Australia has enabled expert advice to be heard and integrated into all national policies and frameworks targeting inclusive play. The shifting structure of disability support in Australia has also meant that the transition period has resulted in a number of tensions. These form out of the inversion of the disability support model, transitioning from the shared needs of the community (addressed with 'block funding') to focusing on the individual needs for clinical support. These tensions reveal that there are significant gaps in the system which has been left unaddressed.

The impact of the newly introduced National Disability Insurance Scheme has been unparalleled by any other structural change in Australia (Butteriss, 2012). It first appeared in the discussions on the future of people with disabilities in Australia at the 2020 Summit, in

2008 (Butteriss, 2012). From this commitment, the Federal Government developed the National Disability Strategy (NDS) (Productivity Commission, 2011) which was proposed as a tax-funded insurance scheme. Now, in 2018, we have seen the rollout of the NDIS to most regions of Australia. It is a scheme which has divided the country, both in term of opinions of its success and viability in the long-term.

The NDIS has restructured the way disability support is provided, moving from a 'bucket funding' structure under the now defunct Department of Ageing, Disability and Home Care (ADHC), to a structure which is individually funded on a needs-basis. This has provided opportunities to better support individual's needs, rather than accommodating those needs within the parameters of block financial budgeting. This change has also triggered a challenging reimagination of social welfare in Australia. The NDIS places the impetus of support on people's reception of left-leaning public policies – a tense debate in Australia.

## **Expert Consultation: Peak bodies and Institutions**

Australia's process of state and Federal policy and regulation development places high value on the consultation of experts and advocates. For example, the commonwealth engages peak bodies to consult with on issues impacting people with disabilities. These bodies, can then, in-turn, represent the interests of thousands of organisations, businesses, and individuals. We have seen the positive influence of such processes which reflect the "nothing about us, without us" slogan in the development of an NDS, which ensured a consistent country-wide approach to the support of our people living with disabilities.

Peak bodies have also been instrumental in identifying the mismatches between policy maker's intent and what policies actually achieve. One such area in which this has occurred is inclusive spatial development. The intention of the new guidelines for inclusive play in New South Wales is to allow for equitable access to play, however, as this engagement with the spatially marginalised has largely gone unfunded in the past it has meant that organizations such as TBO have had to look elsewhere for support and funding, in effect weakening their influence and leading to greater difficulty in pushing their agenda to a political audience.



## Conclusion

It is evident that disability support in Australia is going through a unique and uncertain time of transitioning from one system of thinking to another. While disability, broadly, is addressed in a consistent and visible manner in Australia, the policy mismatches during this transition period often go unrecognised without the voice and support of the research community and advocacy groups.

The *Everyone Can Play* guidelines, while essential to ensuring that the social model of disability is prioritised in our government's thinking, it should be recognised an instrument of change, rather than the change itself. The formal recognition of these guidelines can have significant impact upon the design industry and contribute to creating new standards of inclusion.



## Chapter 3: Unseen Intersectionalities

This chapter addresses the influencing fields of study which combine to create the context for inclusive play for children with disabilities in NSW. An habitually unrecognised area of study, inclusive play for children with disabilities, or ‘inclusive play’ as it will be identified as henceforth, straddles the intersection of Universal Design, Children’s Geographies, and Disability Studies. Each of these fields of study addresses a different aspect of the experiences of play which children with disabilities have, however, they have yet to be brought together in a unified way. This chapter outlines the relevant literatures from each of these disciplines, and points to a new way in which they can be drawn together to progress the knowledge on an often unseen topic.

### Universal Design

Universal, or inclusive, design is the practice of making products and environments accessible, understood, and used by the widest possible user group regardless of their mobility, age, size, or ability (Coleman, Lebbon, Clarkson, & Keates, 2003). Universal design principles have emerged out of the civil rights movement and is representative of the need for intervention in social participation and inclusion efforts. Developed by Architect Ron Mace<sup>1</sup>, UD principles can be applied to concrete things such as products, buildings and open spaces, to intellectual activities such as designing learning programs, and to conceptual things such as policies and practices (Clarkson & Coleman, 2015; Luck, 2018; Morris, 2003). While there is inconsistency in the processes and key terms used within Universal Design (Persson, Åhman, Yngling, & Gulliksen, 2015), there are typically seven key principles which are promoted by institutions such as The [Centre for Universal Design Australia](#), [Centre for Excellence in Universal Design](#) in Ireland, and the [Institute for Human Centred Design](#) in the United States. These principles are:

1. Equitable use
2. Flexibility in Use
3. Simple and Intuitive Use
4. Perceptible Information

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<sup>1</sup> For a brief summary of Ron Mace’s foundational contribution to development of the concepts of universal design see [https://humancentereddesign.org/adp/profiles/1\\_mace.php](https://humancentereddesign.org/adp/profiles/1_mace.php)

5. Tolerance for Error
6. Low Physical Effort and
7. Size and Space Approach for Use<sup>2</sup>

These principles form the foundation of Universal Design's values and guidelines, often appearing as key indicators which measure the success of UD's integration into areas such as education, the built environment, and technology development.

UD in the built environment has developed out of the growing need for 'barrier free'<sup>3</sup> environments in the 1980's from concern to accommodate a quickly ageing population. Such barrier free environments may operate to relieve strain on physical impairments as well as other 'invisible' disabilities which can impact a person's ability to confidently navigate and use a space. Universal design determines that social engagement and participation can be therefore facilitated and improved through thoughtful design processes and features which cater to the widest possible user group, rather than the 'average user'<sup>4</sup>. Foundational works and projects such as Manley's (1986) *New Design for Old*, Laslett's (1989) *A Fresh Map of Life*, and Hamlyn's & the HHF's 1989 *DesignAge* event, brought the idea that the disabled and elderly should not be treated as separate and special groups, but as individuals affected by de-humanising environmental pressures, into public debate. problematising categories such as 'disabled' and 'elderly' prompted a reconsideration of the exclusionary standpoint from which these people, and design, were viewed from. The academic community drew this notion into many disciplines, particularly education and architecture. The result was

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<sup>2</sup> The seven key principles designed by Ron Mace as outlined by these groups:

<http://universaldesignaustralia.net.au/category/aims-of-ud/>

<http://universaldesign.ie/what-is-universal-design/the-7-principles/the-7-principles.html>

<https://humancentereddesign.org/universal-design/principles-universal-design>

<sup>3</sup> The concept of Barrier free design is based on a therapeutic philosophy which emerged after WWII as an approach to rehabilitation. It is a top-down approach which aims to intervene in the environment to make disabled people more comfortable and independent in their lives (Steinfeld & Tauke, 2002).

<sup>4</sup> There has been a great deal of design theory based around the needs, wants, and requirements of the 'average person'. A mythical being who possesses the impossible, 'normalcy'. The following article further discusses this phenomenon within urban design practice:

<https://www.theguardian.com/commentisfree/2015/mar/15/age-friendly-cities-design-future>

The notion of the average user is also suggested in Le Corbusier's (1948) 'Modular man' which created a normative standard of measurement, representing the *male* user. This concept is taught still today in architecture and design schools as the fundamental mode of ensuring spatial functionality. It is criticised as 'masculinist and ableist' by (Buzzi, 2017) who asserts that this modernist Vitruvian man has cursed architecture to become rigid and conforming to the archetypal character of 'the average user'. It can be argued that this practice aggravates anti-UD principles as users who fall outside this model are not catered for, let alone seen by the designers.

development of a holistic understanding of usability, to accommodate for the needs of disabled people, effectively turning the experience of 'others' to the experience of 'us' (Bringolf & Schraner, 2009; Clarkson & Coleman, 2015).

Inclusive practices were integrated into legislation and policy in the late 1990's thanks to the growing visibility of UD in academic discussions. Therefore, the ideas of inclusion and civil rights (to access and participate) began to be instilled in design discourse, allowing for a broader range of access needs to be met (Clarkson & Coleman, 2015). This was exercised as a series of legislative changes e.g. The *Australian Disability Discrimination Act* (1992) and the *Convention on the Rights of Persons with a Disability* (2007), and the *Building Code of Australia* (1996) These legislative changes brought flexibility and the consideration of formerly unrecognised limitations such as visual or auditory impairment, wheelchair and walker use, and intellectual disability. These changes increasingly allowed for the right of an individual to have equitable access to the built environment, to be extended to incorporate individuals who may not have been previously considered.

International and Australian research in this space has also been growing since the early 2000's (Wooley 2013; Woolley & Lowe, 2013, Woolley et al. 2006, Burke 2013, 2012, Stafford 2017a; Goodley & Runswick-cole, 2010), making UD discourse prominent in the design space amongst practitioners and theorists of spatial design. The idea that inaccessibility is thrust upon an individual by inadequate design, inconsiderate services and environments, and cultural stereotypes is widely accepted now in contemporary architectural and design practices (Clarkson & Coleman, 2015). New concerns have now emerged in how to deliver UD principles in practice. In particular, debate between Government legislated and UD building standards; A philosophical rift which has emerged between two ideals of 'best practice' in design. In Australia, principles of UD are often highlighted by national groups and are included in prominent political discourse. They are, however, overshadowed by the realities of spatial design, where very few UD standards are enforced as 'hard' policy and regulatory statements (Jones, 2014). Steinfeld and Tauke (2002) address one explanation for limited UD principles being used in the creation of public spaces, suggesting that a number of misconceptions about UD exist. There is a disagreement on how UD impacts things such as overall (long-term) cost, spatial requirements, and aesthetics. Miller and Hayward (2016), relay how this debate fractures productivity in building inclusive communities for disabled people by the prioritising

of short-term spending, over long-term social changes. Following this line of thought, Jones (2014) advises that much of the resistance to UD is not due to fundamental disagreement with its principles, but because of this short-term prioritising, suggesting that political opportunism plays a role in the resistance against UD.

## Childhood Disability Research

The study of Childhood disability contributes to the active engagement in and valuing of children's voices in matters which concern them. The sub-discipline of Children's Geographies has been responsible for many development in the way childhood disability is understood and spoken about. Influenced by developmental and environmental psychology, Marxian theory, and feminist studies, the grounding works of Aitken (2001); Holloway (2014); and Holloway and Valentine (2000) explore the nature of childhood, positioning it in the centre of issues such as scale, risk, voice, and personhood. Emerging out of the discipline of geography, children's geography aims to reframe the processes of investigating spatial and social connections to value children and their unique experiences and understandings. In particular, how this perspective can impact, reduce, and create barriers to the experience of power and inclusion. Central to its theme, children's geography approaches these power relations by breaking down the academic hegemony of adult ableism<sup>5</sup>, providing more space for children's lifeworlds<sup>6</sup> (Shillington & Murnaghan, 2016).

Children's geography's approach to understanding disability also breaks down power relations in ableist discourse (Rempel, 2017). It makes connections between intersectionalities which are not often addressed in other disciplines, such as 'children', 'youth, and 'disability'. There still remains a need for the alterity of disabled children to be further recognised by the discipline. Research such as that by L. Holt (2004b) and Skelton and Valentine (2003) discuss disability within the children's geography context. However, there remains a dramatic underrepresentation of the experiences of children whose have

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<sup>5</sup> Ableism refers to discrimination in favour of able-bodied people. Hodge and Runswick-Cole (2013) outline its role in constructing exclusionary environments for disabled children.

<sup>6</sup> Here, lifeworld refers to the world in which disabled children live out their experiences (see Husserl, 1936 for further information on lifeworlds). This accounts for the spaces which children inhabit and the subjective realities which children act out. It is used in this context to highlight a point of difference between the life experiences of adults and children, with the intention of making more intellectual space for children's experiences and knowledge.

disabilities. Jones (2008) and Pyer et al. (2010) recommend that the momentum created by such people be continued as there is a wide gap in the literature which is representative of the 'Othering' which not only disabled children experience, but that also the study of disabled children encounter.

Recognising the voice of disabled children in the wider context of children's geography reforms the way disabled children are understood and represented. This challenges the values which place adults as fully-formed, or 'whole' people and children, therefore, as semi-formed and lacking true personhood. (Browne, 2016) addresses the nature of this dismissal of personhood, acknowledging and criticising the adultist rhetoric which dismisses the intent and agency of a child. (Heinze, 2000) places this adultist discourse as a mythic representation of the pastoral child. This is supported by (Aitken, 2001) who comments on how children are rarely represented as politically minded, they are instead often symbolically represented as a tokenistic embodiment of this idyllic nature. These notions become dislodged when disabled children are conceived as valid informers, effectively breaking down taken-for-granted scalar thinking which diminishes the authority of children in their own lives (Ansell, 2009).

The way disability is understood, represented, and cared for within the Australian context reflects the aims of developing more inclusive and progressive discourse around disability and the disabled. In the contemporary Australian context, the 'social model of disability' is what informs all current legislative and best-practice positions. This approach, coined by Mike Oliver in 1983 (Oliver, 1983) replaced the medical model of disability which situates disability within the 'medical gaze' (Foucault, 1963). In medicalised representations, disability is typically represented as an abnormality which is looked at from a paternalistic viewpoint, suggesting that disability be seen as something which needs to be fixed in order to bring one back to a state of normalcy. By rejecting this understanding of disability, the burden of abnormality is removed from the individual, creating an environment which better respects, better understands, and better integrates people with disabilities into communities.

Disabled children often do not have these same rights extended to them. Prevailing ideas about children's inability to self-advocate prevents them from being put in the same 'competent' category as disabled adults. As a result, disabled children are often doubly neglected in social or legislative changes aimed to positively impact the lives of the disabled.

In this instance, the experiences of disabled children are reverted to a Cartesian understanding which subjects them to clinical care type measures rather than measures of support; to work on instead of to working with. Also, commonly occurring is the idea that measures which are intended to cater to the carers of disabled children also cover the needs of the disabled children themselves. Jeanes and Magee (2012) indicates how this misrepresentation of disabled children can lead to invisibility in contexts such as education, support funding, social narratives, public spaces, and policy.

The recent introduction of a National Disability Insurance scheme (NDIS) in Australia has led to many changes in the disability sector and for those whose disabilities are not supported by their environment. The integration of a marketized system of 'disability care'<sup>7</sup>, as argued by (Laragy, Fisher, Purcal, & Jenkinson, 2015) distinguishes Australia as a unique environment for the treatment of people with disabilities. Miller and Hayward (2016) outline how this system can work to further alienate those disadvantaged by disability by putting additional pressures on the individual's ability to function independently. It has also been suggested by Laragy et al. (2015) that the NDIS system inappropriately draws attention away from the community and toward the individual, often leaving community supports severely underfunded and under supported. Diverting the focus onto individual care plans through the means of cost incentivising runs in line with Muir and Salignac (2017) who argue that any kind of social welfare integrated through a market system is bound for inequality as the demand for profit overtakes the demand for meeting needs. This suggests that financially incentivising providers to cater to the needs of the disabled puts too much emphasis on the potential economic benefit rather than the social benefit.

Acknowledging that the current climate of the disability sector in Australia is heavily impacted by such structural realities, Carey et al. (2018) point to the political incentivisation of backing a neoliberal approach to the care of the disabled. They address the contradiction of creating 'new' and 'better' ways of caring for the disabled, whilst simultaneously maintaining the status-quo of a neoliberal philosophy. There is also a body of work which suggests that this

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<sup>7</sup> Note, this is different from medical care as the NDIS specifically outlines their responsibility for care as only going as far as covering things which are directly related to a person's permanent disability which impacts a person's ability to function like an 'average' person. This separation of 'disability' and 'medical' remains a point of friction for disability support organisations, NGO's, advocacy groups as well people with disabilities as the onus of responsibility is passed between the relevant health body and the NDIA.



neoliberal structure creates the potential for political opportunism where popularity is secured by emphasising matters which impact the disabled and their support networks. Cutler and Waine (1997) and Greener (2008) agree with this, stating that there is minimal incentive for the average person (more specifically in this instance, the person who is not familiar with the limiting power of disability) to make improvements aimed for the long-term.

## **Discussion**

This literature review has addressed the key policy to practice realities within Universal Design and Children's Disability Studies. It has identified several key ideas which will provide context and guide my research project to address its key questions. This review has highlighted how child representation influences their visibility, specifically, the underrepresentation of disabled children within policy aimed at assisting disabled people, design literature, and within the built environment. It has uncovered the political incentivisation to favour short-term gains over long-term social changes, such as that which UD principles within the built environment would bring. The Australian context of disability support is also explored, showing that prevailing neoliberal philosophies and marketisation of the third-sector dramatically impacts the ability for disabled children to be supported appropriately. The paper also addresses the impact of disabled children's personhood and how it is often regarded as semi-whole. Gaps in the literature have been made evident by this review. The Intersectionalities of research on 'children', disability' and 'inclusive design' are not sufficiently addressed. This will be followed in my research project as understanding disabled children's spaces and experiences within them is essential to being able to confidently support them.



## **Chapter 4 – Studying Inclusive Play for Disabled Children: The Methodological Challenges**

Research with children who have disabilities is challenging. Ethical considerations arising from working with this group include questions of informed consent, risk, and how to match effective methods to ethical oversight. There is a notable body of work providing guidance on best-practice approaches for research with children with disabilities which will be explored in this chapter. And in many ways, however, the difficulties acknowledged in this literature have meant there are significant gaps in the development of research methods which prioritise the child over their networks of care, and as a result disabled children's everyday experiences remain misunderstood (Shakespeare, 2015; Stalker et al., 2012). This chapter traces the way these challenges were addressed in this research project by outlining the methodological approach adopted and the methods which were developed and applied to collect the research data.

### **Key issues**

The lived experiences of children who have disabilities are perhaps the most valuable source of research insight for understanding the core issues focused on in this research (See Overboe, 1999 for discussion on the 'lived experience' of people with disabilities being more than their disability). Societal assumptions about a child's capacity to validly contribute has historically been shaped by adultist ideas of personhood. As a result, children have been judged as unable to contribute to valuable research because of how they move and communicate (Ehrich, 1994; Holt, 2004a). Children's voices in research are also often reflected upon from a position of ableism and power. This has resulted in alternative ways of expression being labelled as 'complex communication needs' (CCN), and therefore suggesting that they are in some-way less-valuable, or less-adequate. Stafford (2017b) identifies how these assumptions cause children with CCN to be left out of research, or studied through their support networks. Fears of these challenges have also resulted in concerns over the ethical considerations of researching with children who have experiences of disability. The ethical attention is considered to be great and negotiating ethical approvals challenging, leading many research projects to avoid direct engagement with children with disabilities and turning

to methods that seek alternative data sources (O' Shea, Pavia, Dyer, Craddock, & Murphy, 2016:18 comments on the 'impracticality' of user-consultation).

Such anxiety has perhaps helped to establish a significant disciplinary approach in the field of Disability Studies – an approach that can be reasonably labelled as 'researching by-proxy', that is consulting with parents, carers, and the wider support network, but not the children themselves (Shakespeare, 2005; Stafford, 2017b). As a result, many researchers opt to use approaches that limit opportunities to deeply and conscientiously engage in the lives and experiences of their target research group (Holt, 2010; James & James, 2008; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012; Stafford, 2017a 2017 b).

In contrast, there has been significant development in appropriate research methods targeted at understanding the experiences of children with disabilities. Notably Davis, Watson and Cunningham-Burley (2008) reflect upon ethnographic and emancipatory research influences with disabled children. This work is reflective of a push-back against a preoccupation with narratives of dependence in research about childhood disability prior to the 1990's. Pyer et al. (2010) also reflect on those who have made great strides in developing best-practice when researching with children with disabilities. Of particular note Valentine (2003) who promotes the idea of fluidity in research design to cater to the diverse needs of children with disabilities.

The design approach adopted for this research has attempted to address these issues in three important ways:

- the project seeks to evaluate an often taken-for-granted assumption that UD equates to more accessible spaces and therefore better social inclusion of the spatially marginalised;
- the research prioritises children's own evaluations and experiences as an appropriate way to pursue the research questions; and
- the research places confidence in the value of these children's voices through research methods designed for researching with children who have experiences of disability.

## **Approaching Ethics Approval**

This research was explicitly designed as a pilot study to develop and trial a research approach aimed at addressing existing research limitations in the field of children's disability, and giving

authentic voice to the experiences of children with disabilities in an ethically conscientious way. The research design was discussed at length with my supervisor and an advisor from Touched By Olivia Foundation prior to submission to the Macquarie University Human Research Ethics Committee (HREC). Both encouraged me to explore ways of engaging directly with the children using the inclusive playspaces – to take them seriously as the centre of the research topic.

The ethics application process was challenging as the goal of facilitating the diverse group of research participants meant there was a need for flexibility and creativity in the research design. This challenge was met by approaching the research questions and methods by focusing on thinking about what the data to be drawn into addressing the research questions from the experience of the children might look like. This meant that instead of presenting a list of explicit survey or interview questions in the ethics application, the research intention was detailed, outlining how the methods aimed to draw out particular themes and discussion topics. The justification of this approach was to develop a research approach that would accommodate the research participants' diverse experiences and perspectives, as well as the varying interpretation and communication abilities present in the group. As a result of this, it was recognised that there could not be one set of questions deemed appropriate to use with all respondents in a one-size-fits-all approach.

The research design, therefore, draws on current discussions in the fields of study discussed in Chapter 3 – Children's Geography, Disability Studies, and Universal Design – to frame the experiences of children with disabilities in universally designed spaces through the lenses of the social model of disability and geographies of care. Existing critical discussion on the success of UD has greatly influenced the methodological approach of this research as it pushes for collaborative research to be part of the design process. Much like how UD utilises the trialled technique of 'designing with' (Beckett, Holt, & Moore, 2012; P. Jones, 2014; Torrens, 2000) the user group to create more functional spaces, this research implements the same techniques in spatial evaluation. Where this research differs from the established practices of these three disciplines is in the development of research methods which break down the layers of interpretation added to stories of children's experiences when they're studied by-proxy.

The methods applied in the research were developed iteratively with several trials and re-evaluations which identified the challenges of researching with young children and the methodological design elements which overcome these challenges. The research method trials were informally conducted with two young children aged of six and nine. They resulted in several re-designs of the case study location map to better reflect the used spaces at the playground, and to better utilise high colour contrast for more effective interpretation. The trials also shaped the thematic approach to research questions to highlight the importance of flexibility in design.

The ethical challenge of the research is the need to highlight the voices of the research participants effectively and conscientiously while still providing them with suitable support to deliver ethically sound research. The innovations designed for this research are the elevation of the child to the equal ontological level of *co-researcher*, and the maintenance of a typical and supportive care relationship with the child's parents, carers, siblings etc. whilst the child is engaged in research, named the *support-network*. Labelling the research participants as co-researchers puts them in a position of authority and acknowledges them as 'user-experts' (Azzopardi & Grech, 2012; Ringaert, 2001). It allows their positionality to be validated and therefore legitimately contribute to the knowledge on the experiences of children who have disabilities. To ensure that the contribution of the co-researchers was maintaining the ethical expectations of sound research meant that maintaining the co-researcher's safety was highly prioritised. The support network refers to the physical and emotional support provided by the child's family and community. This dynamic is encouraged during the research to provide a typical level of support so as to maintain a usual playspace visit. The intention is to engage with the co-researchers in a comfortable setting and with typical supports. Wright, Roberts, Bowman, and Crettenden (2018) identify how important familial relationships are when conducting research and comment on how encouraging this relationship strengthens research without compromising the voice of the child. This research follows their position, and further contributes to his perspective by emphasising the value of the support network dynamic in the context of research ethics.

The project received ethics approval from the Macquarie University Human Research Ethics Committee (Approval #52017088) on December 22, 2017. A subsequent request to amend

the approval to allow interviews with a wider range of stakeholders was subsequently approved on 17 April 2018 (See Appendix 1 for details of the ethics approvals).

## Research Methods

Three methods, focusing on ethical grounding and flexibility of delivery, were ultimately included in the research design:

- Playspace exploration
- Participatory mapping exercise
- Stakeholder interviews

This section discusses the rationale and practical application of the three developed methods, and context on the challenges faced throughout the method development and trial period.

The research was conducted with four children between the ages of six and twelve, who have varying experiences of disability. These include, but are not limited to Autism Spectrum Disorder (ASD), intellectual disability, and physical disability.

### *Playspace Exploration*

The *Playspace Exploration* is a guided spatial exploration of Livvi's Place, Ryde, which is entirely directed by the young person, or *co-researcher*, with the support of their typical support network (e.g. parent, grandparent, carer etc.). The child led the researcher through Livvi's Place, stopping at each area or piece of equipment as they decided. They were given the opportunity to play on the equipment, interact with other playground users, and generally have fun. Questions were asked by the researcher and discussion was prompted on each area as they were reached. Stories about what the children liked or disliked about the space, past experiences, and any interesting ways they might use the space or equipment were highly encouraged.

As some of the co-researchers are non-verbal, or were uncomfortable with verbal communication, the research design needed to be flexible in order to facilitated alternative ways of communication. For example, the co-researcher's body language was recorded by note taking and used to give impressions about the spaces they engaged with. This proved to

be important to maintain the child's presence throughout the research when they had CCN. The child's support network was present and engaged during the playspace exploration as they were considered an important physical and emotional support in this interaction. They assisted with encouraging, physically supporting, and interpretation for, the child.

The rationale for this method was to explicitly engage disabled children in research about them; to allow them to direct the focus of the data collection, to introduce the direction the research took and to control timing and placement of the research activities. This is done to extend their rights (UN General Assembly, 1989) and allow for a re-working of social narratives which regard disabled children as incapable of self-determination and agency. This follows the larger ambitions of the research project which aim to give voice to children with disabilities, so that we may learn about their experiences first-hand. To do this, the children were placed as decision makers in the research, determining where is explored, what the conversation content is, and when the research activity ended.

The strength of this approach is in its ability to negotiate a safe environment which also allows for the co-researchers to confidently share their experiences by maintaining an appropriate level of physical and emotional support. The presence of the child's support network was reviewed through several iterations, and judged to be essential in creating a positive experience in which the co-researchers could confidently communicate their knowledge. The support network's presence provides more opportunity for effective communication which would otherwise be challenging due to the range of the children's age as well as their interpretation and communication abilities. This is important to the value of the research method as it allows for a custom designed and ethically responsible research method to be used with children who have experiences of disability.

### *Participatory Mapping Exercise*

The participatory mapping exercise was a supplementary exercise to the playspace exploration. It asked the co-researchers, with the support of their support network, to visually represent the stories and opinions explored on a map of Livvi's Place. Due to the broad range of abilities and needs, the practice of this mapping exercise was kept as flexible as possible. It was largely an interpretive exercise which gathered information from several sources, to





- Drawing images on the map
- circling the 'good' and/or 'bad' areas
- Writing key anecdote trigger words on the relevant areas
- Placing stickers and suggesting meanings to place on them
- Pointing to areas or features and verbally recalling the information
- Support person/s prompting the co-researcher, or speaking on their behalf, to tell stories about specific aspects of the playspace

Visual representation of these experiences enables the recognition of user-experts (Ringaert, 2001) sharing of expert knowledge which is otherwise difficult to obtain. For example, GIS techniques, such as that adopted by Preto et al. (2016); Wridt (2010); and Zhou, Li, and Larsen (2016), are used to assist children to overcome communication barriers similar to those which the participants in this research project face. This is especially useful when gathering knowledge from respondents who may experience limitations with more structured research strategies, such as interviews.

### *Stakeholder Interviews*

The stakeholder interviews are with five people in key positions within the inclusive play landscape. They are people such as local councillors and local government staff, disability advocates, and members of advocacy groups and organisations within the disability sector. The interviews were designed to be semi structured and intensive in style (Dunn, 2005; Harré, 1979; Sayer, 1992). To effectively manage the broad range of respondents' involvement in the inclusive play of children with disabilities, the interview questions were customised for each respondent and focused on initiating conversation on the opportunities for disabled children to experience inclusive play with the aim of providing additional background to the research, framing the experiences of the co-researchers in a broader social, political, and geographical context. Specifically, these interviews addressed the third research question: What is being done by local and state Government, as well as communities to facilitate equitable access to play in Ryde? The insight provided by the interview respondents have shaped the final evaluation of the current state of play for children with disabilities in Ryde. Some of the key items which are addressed in these questions are:

- What their personal involvement is in the state of inclusive play

- What their understanding is of the major challenges which children with disabilities face during play and;
- How have these challenges been addressed in Ryde, NSW

The interviews were recorded and transcribed to maintain consistency in analysis. These interviews have been used to provide context to the geographical, political, and social framing of the research within Ryde, providing the reader with a better understanding of the motivations and implications of this research project.

## Conclusions

The social inclusion of disabled children is an often-neglected community concern. Little emphasis on the needs of this demographic consequently results in invisibility in Government policy and social narratives; A pattern which is reflected in academia. Vulnerable communities, such as disabled children, are often not engaged in research out of anxiety of inappropriate methodological choices. This research project challenges this reluctance and bridges the gap in academic research by developing and trialling research methods which are ethically conscientious and suitable to be used with a vulnerable demographic like children who have disabilities.

The methods developed focus on experiential and narrative data guided and shaped by the young person, or co-researcher. Essential to the efficacy of the methods is the emphasis on flexibility of delivery and response. This is intended to cater to a wide range of communication and interpretation abilities so that they are able to participate in any way that they can. Also, important to the value of these methods is the positioning of the young person as co-researcher, giving them the authority to direct, initiate, and discontinue research as they see fit. The maintenance of a 'usual' support-network dynamic within the research reinforces and supports the authority given to the child as co-researcher while providing a highly valuable level of stability and support which is often neglected in other research with disabled children.

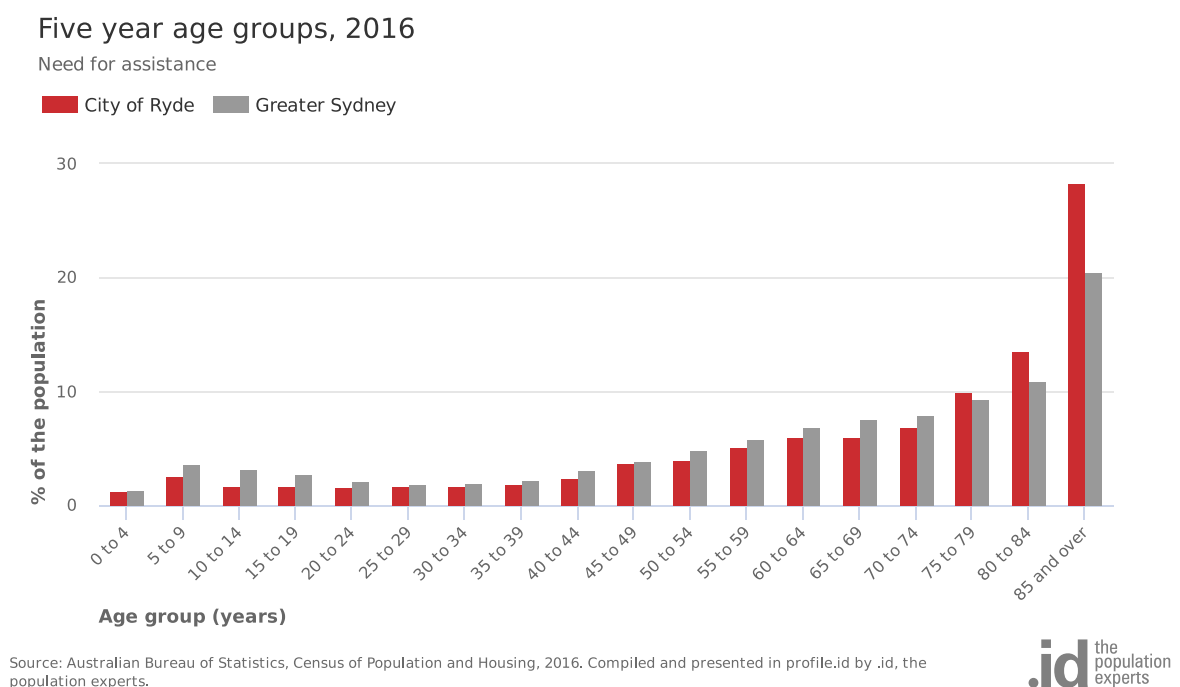
The methods adopted here have limited use as they were specifically designed and intended to be used with children with disabilities and their support network. Therefore, making it unsuitable as a sampling technique which makes inferences about larger populations. Their strength, however, also lies within this small-scale design as there is subsequently room for

flexibility, diversity, and in-depth investigation. Despite the in-depth narrative intentions of these research methods, there is still potential for expansion of the demographic and geographical parameters in future research, as the intended future research will continue to focus on the narratives of individuals to increase the ability to provide disabled children equitable access to play.

## Chapter 5: Playing in Ryde

The City of Ryde in many ways exemplifies Australian suburbia. Demographically, it is culturally diverse and includes a growing population of young families. It is in many ways typical of the growing and changing image of middle-Australia in its demographic and political landscape. Additionally, there is a large number of young people who require assistance in everyday core activities living in Ryde LGA, which has contributed to its development as one of Australia's most progressive LGA's in their engagement with people who have disabilities, particularly concerning the care and support of young children (3.1% of the population of 0-9 year olds living in the City of Ryde required assistance in 2016).

**Figure 5.1: Ryde LGA Population Age Structure**



Ryde LGA hosts many diverse disability support services (see figure 5.2 below) which are rapidly increasing since the advent of the NDIA. Touched by Olivia Foundation is one such NGO which is making waves in the political sphere and successfully promoting their agenda State-wide – to allow everyone to have the opportunity to play. TBO is a primary partner of this research project, and their playspace in Ryde, 'Livvi's Place', which was opened in 2013 has served as the location for conducting research in this MRes project. This chapter will

introduce the location case study, Livvi's Place, Ryde, where the playground explorations and participant mapping exercises were conducted and discuss the local context of inclusive play.

**Figure 5.2 Disability support and advocacy groups located in Ryde LGA**



## The State of Play in Ryde LGA

The state of play for children with disabilities in NSW has been at the centre of many recent regulatory, design industry, and community changes in recent years. Most notably, the announcement of new NSW guidelines for all public parks and playgrounds to meet and exceed the principles of Universal Design. The intention of the guidelines is to ensure that these public spaces are accessible, functional, and enjoyable for all who use them, no matter their age, size, or ability.

The choice of Minister for Planning, Anthony Roberts, announcing the 'Everyone Can Play' NSW Stage Government guidelines in Ryde LGA, in Sydney's North, is a politically strategic move which lends praise to the efforts which Ryde City Council have made to push beyond the regulatory requirements of public space in NSW, and setting a new standard Australia wide.

Ryde is home to one of Australia's leading inclusive playgrounds, Livvi's Place, developed collaboratively by Ryde Council with local business and government support and substantial

third-sector involvement, opening in 2013. The context of inclusive play in Ryde LGA owes a great deal to the development of this space, and the organisation behind it, Touched by Olivia Foundation. The way play is understood in Ryde has developed around the values which Livvi's Place promotes (e.g. that play is a right for everyone to experience). The engagement with inclusive design practices in Ryde LGA has become a point of Pride for the community, and a source of inspiration for families with children with disabilities and playground developers in other regions.

Ryde LGA's progressive grasp of inclusive playspace development is reflected in their policies, most notably the 'Children's Play Implementation Plan' (2013) which identifies playground design frameworks which influence the design and rhetoric surrounding inclusive play in Ryde (2013:69-88). In addition, their 'Social Inclusion Advisory Committee', and the newly instated 'Playground Panel' has placed Ryde City Council ahead in inclusive spatial design, fixing their public space as a site of above-standard community engagement.

On paper, Ryde LGA ticks all the boxes to be considered greatly ahead of other LGA's. However, now that some of the main goals are much closer to being reached, where do they go from here? The ambitions for Ryde's future engagement with inclusive play was expressed by Mayor of the City of Ryde, Mr Jerome Laxale who stated that the City of Ryde will "make every future regional playground fully inclusive and ensure that there are inclusive elements in all district playgrounds" (Interview response with Mayor of the City of Ryde). Although this ambition is in-line with the forerunners for inclusive play advocacy, the gap which remains to be filled in any concrete or legislative way is the research which informs what exactly those 'inclusive elements' are. A triggering question for this research project is how to bridge this gap and increase the knowledge on experiences of inclusive play.

Measurement of the success of inclusive playspace promotion is also something which was not explicitly identified as an ambition for future development of Ryde LGA or NSW Government.

Bec Ho, Executive Officer of TBO, cites the success of inclusive play to be dependent on "further education, training, and incentives". These strongly echo the sentiments of City of Sydney Councillor, Craig Chung, who identifies the major hurdle limiting the impact of the

NSW Everyone Can Play guidelines is the engagement with inclusive design as a “design principle, rather than a design philosophy”. He suggests that until inclusive space is included as regulation, it is unlikely to be

## **Strategic Need for Inclusive Playspaces**

One of the key roles of Local Governments is directing the effective and considerate use of funding. Key demographic drivers and community priorities typically indicate what areas these funds should be channelled into. Considering the strategic need for inclusive playspaces in Ryde brings up the question “Why would we create playspaces which don’t cater to the entire community, especially when everyone contributes to the funding which would be used?”.

A concern voiced by many advocate groups centres around the journey of the social model of disability from theory to praxis. There is a consistent privilege over right mentality which seeps into social discourse by being reaffirmed through the actions of people and Governments. Prioritising the able-bodied populous of an LGA in public space development is an example of how this occurs, and in-effect how exclusion of diverse populations is reinforced and often ‘silent’.

The benefits of play on the development of young children is clear and well-cited. But, we are at a juncture in this policy to praxis journey as the children who would benefit most from the opportunity to play are often the ones not able to access or use playspaces. Ryde LGA, through the lobbying and support of TBO, has developed an action plan which prioritises the active engagement with experts and expert-users to develop their knowledge on the impacts of inclusive design. This action not only engages with the people of Ryde LGA and their needs, but also sets an example which many LGA’s nation-wide are following.

In addition to the community context of the need for inclusive play, the political security of supporting the needs of the people who reside in Ryde is paramount in influencing the procurement of state funding to develop policy guidelines and innovative public space. The challenging task of helping the incredibly diverse community of Ryde acknowledge the benefit and need for inclusive thought and universal design in both policy and public space is important to ensuring that the community is catered for.



The demographic drivers of population and political alignment has worked in favour for the mission of inclusive play in Ryde LGA. It has served to develop Ryde into an exemplar for other LGA's and used as a platform for both the Labor party and the coalition to voice their attention to the need of young children with disabilities and their caregivers.

## **Touched by Olivia Foundation and Livvi's Place**

Touched by Olivia foundation was established by John and Justine Perkins in 2006 after the tragic passing of their daughter Olivia. From this loss they were moved to promote their message of inclusion and care to the community. Their mission statement is to bring the joy of play to the children and families who have challenges accessing spaces and connecting with the community. These often being young families who have children with disabilities. Their endeavour is in response to their own experiences of inaccessible play, and is aimed to ensure that one's abilities were no longer a limitation. With this ambition in mind and after several years of development, Touched by Olivia Foundation was born in Olivia Perkins' memory.

Touched by Olivia foundation have been instrumental to the engagement of State and Local Governments in the

**Figure 5.3 Livvi's Place, Ryde**



Livvi's place playground made in collaboration with Touched by Olivia Foundation in 2013 is the City of Ryde's first inclusively designed playspace. It has been created in line with Universal Design principles which aim to make spaces accessible and functional for all who use them, regardless of their ability, size, or strength. In this way, Livvi's place is a unique engagement of public space which is considerate to the diversity of its users. Most users of Livvi's Place are unaware of the lengthy process which took place to ensure this space's development and governmental support. It is representative of years of lobbying and education about the need for public spaces which support the entire community.

The intention of Livvi's Place, is not to be a playground *for* disabled children. Rather, it is a place for all, where everyone can feel welcomed and protected. Livvi's Place has acted as a community facilitator of friendship and positive policy change since discussion of it began in the early stages of TBO. Walking into Livvi's place, it is clear that it isn't like any other playground. It has soft rubber ground with high colour contrast from the equipment. The extra wide and gently sloping paths allow the users to circulate the space with ease. Wheelchairs, walkers, and the physically challenged are welcomed with flowing design and forgiving spaces. Those with unseen disabilities are also catered for at Livvi's Place. Sensorially quieting spaces and tactile areas are integrated with sensory stimulating experiences like swings and flying foxes.

At Livvi's Place disability is encouraged to be normalised amongst the users. Those who have disabilities are not expected to play in a different area, or use different equipment. It's about playing with your friends, not next to them. A unanimously favourite feature is the flying fox. There are two seat options, one with a ledge for someone to stand on, and one with a harnessed chair for someone to sit in. Watching the way children who have experiences of disability interact with others at Livvi's place is unique and a great example of the potential which considerate space can provide.

Parents and carers comment that they feel safe letting their children explore and have dignity of risk because the playground is completely fenced off, the floor is soft, and the users more understanding of the challenges which their children face as they also have experiences of disability or have been exposed to them through playing there. Children with disabilities are engaged with, given the opportunity to learn and to experience interactive play, something

which is hard to effectively facilitate elsewhere, especially in such a large and disconnected city.



## Chapter 6 Inclusive Play: The Experience

The experience of play for children with disabilities is diverse and often complex. It reflects not only the child's personal challenges, but also the context of their support networks and communities. This chapter presents the research data which was collected during field work, presented as narrative representations of play for children with disabilities. All stories take place at the location case study, Livvi's Place in the City of Ryde, NSW. Before presenting the data, let me introduce my co-researchers. Pseudonyms have been used to maintain the co-researcher's confidentiality.

### The Co-Researchers

#### *Melanie*

When I first spotted Melanie in the playground, it was clear that she was much smaller than most seven-year olds. She stood there with her mother and sister, aided by a bright yellow walking frame which she used with confidence.

We made our introductions as Melanie edged over, and before we knew it she was flying down the hill having accidentally lifted her legs a little too high and pushed the wheels a little too close to the edge. She shot down the slope, holding on with all her might a look of stricken panic on her face. When she finally smoothed to a stand-still she had tears in her eyes, unable to push forward any words. "As you can see, she does need some help, even here" her mother said, laughing and trying to make light of the event and encourage a smile.

Melanie has a physical disability which has had her whole life. I asked her about the things she doesn't like and finds scary. Unsurprisingly they are the things that she cannot do on her own, or that which causes some uncertainty for her body control and movement, steep hills, and insecure swing seats for example.

Her older sister plays on the flying fox, but Melanie prefers to watch from afar. Melanie's contribution to the day wasn't explicitly verbal. She is softly spoken and shy to contribute her opinions. Her physical triumphs however showed more than what words could convey. She likes to be in charge but needs to ask her mum for help for almost everything. Realistically,

there is only one or two things which she can access fully independently at Livvi's Place. This small privilege gives her something much more than simply the experience of play. It provides opportunities to engage with her siblings, other children, and to challenge herself to build her confidence. And most importantly, it makes her smile.

"Providing Melanie with the ability to participate, at least in one or two ways, opens so many doors", her mother says to me. We sit back and watch another young boy of Melanie's age who is also using a walker. Their parents give each other a reassuring glance and a nod, as if to convey mutual understanding. Melanie notices and thinks it's cool that the boy has the exact same walker as her. She compares their stickers.

## *Ben*

When I met Ben, he was preoccupied with the flying fox. His dad was pulling him along as fast as he could as Ben excitedly braced himself for the inevitable jolting impact at the end of the line. This is the part he likes the most.

Ben is six years old and prefers to quietly observe as I speak with his family. His mother tells me he enjoys the thrill-seeking sensory activities. She comments on how wonderful it is for him to be able to use the flying fox right next to his sister, who prefers the standing one. Ben has been diagnosed with Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD), diagnoses which severely impact his socialisation and opportunities to meet people. He likes the "feeling of falling" and tells me that he has chosen his favourite parts in Livvi's place, the flying fox and the basket swing, because of this. Livvi's Place provides him with much needed space and sensory control, in an environment which also makes his family feel safe.

After a high-sensory experience Ben likes to centre himself by hiding away somewhere quiet and still. The tunnel at Livvi's Place is his favourite for this. His sister tells me that he used to run away and it was very scary. He doesn't do this anymore, but it's always something on the mind of his family.

Ben's social skills are limited and at times can be a great source of anxiety for him. When he's confronted by unfamiliar people or conversation topics his first reaction is to keep quiet. It

took some time for Ben to warm to me. We eventually bonded over our mutual love for violent video games. This was a talking point which had him fixed for over an hour. Ben's interactions with other children, much like his conversation with me, is facilitated by common interests. As I sat and spoke with Ben, he notices another young boy with a Beyblade<sup>8</sup>. The connection is instant and intense.

These moments are considered triumphant by Ben's parents who have watched him overcome a lot of challenges. Seeing him in conversation and playing with others in a safe a carefully curated environment means that their attention can be focused on encouraging him to learn and grow.

## *Mia*

Mia is mostly non-verbal, but her enthusiasm for exploring and sharing is how she expresses her personality. I met Mia whilst she was in the sand pit at Livvi's Place. She enjoys all things nature and texture. Her mother explains to me that she could spend all day in the sandpit, scooping up sand and letting it run through her fingers, she loves it that much.

Mia and her family have had a complicated journey. To-date, it is not known what Mia's full diagnosis is. She currently works with uncertain diagnoses of skeletal Dysplasia, ASD, a severe language delay, and moderate intellectual disability. Despite these challenges, Mia has been flourishing in her speech development and interaction skills with others, moving on from Auslan to spoken word and direct communication.

She does not venture too far toward the other play equipment and prefers to keep herself busy with the sand, the grass, the bushes, and the crunchy leaves fallen on the ground. She led me by my hand through the bushes, along the wood-chip garden beds, and back into the sandpit, showing me intensely the things she enjoys, and physically avoiding that which she does not.

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<sup>8</sup> Beyblades are spinning tops which are promoted by the Japanese manga series *Bakuten Shūto Beiburēdo* (Explosive Shoot Beyblade).

Mia's connection with her surroundings is nurtured in this space. It provides her the low-sensory stimulation which she prefers, in a calm and relaxed environment.

She has little interest in the other children around her and prefers to focus her attention on her hands and feet – where she receives sensory stimulation. Mia's family have persevered through the social challenges which Mia's disability has triggered. Since discovering Livvi's Place, they are now confident and excited to communicate with me that, for the first time, other children are approaching Mia to play with her and sit by her.

Although Mia has little verbal communication and interest in social interaction, seeing her thrive and learn through new experiences is something invaluable.

## *Aaron*

Aaron's vision for playgrounds is one where they are all inclusive. He speaks from his experiences and hopes that he can help other children with circumstances like his to be the best that they can be. He says to me that he thinks all playgrounds should look like Livvi's Place, and that "it just makes sense".

Aaron is 12 years old and uses a wheelchair. He has taken on a challenging advocacy role for inclusive playgrounds with enthusiasm and confidence. He can be shy about sharing his opinions but is firm in his beliefs. He has been involved with Touched by Olivia for several years and seen spaces like Livvi's Place grow from an idea to a reality.

When I first met Aaron, he straight away told me that he would prefer just to stay in a quiet shady space and talk. He was exhausted from medical tests and physiotherapy the day before. He says this happens a lot and that he often doesn't feel like doing much as his therapy supports take a lot out of him. His mother told me that he insisted on coming to meet me, even though he was tired. This small glimpse into Aaron's daily life shows his determination and strength of character.

He spoke articulately about the challenges which he has faced when getting around and spending time with his friends.



Aaron spoke in great depth about the physical barriers often faced by people who use a wheelchair like he does. It was, admittedly, things which I had never before considered. His kind approach to educating me is a testament to his success as an inclusive playspace champion – Something which many adults can learn from.

## **Experiencing the Playspaces**

The following section of this chapter has been arranged as place-based vignettes from three locations at Livvi's Place which show a diversity of experience.

To ensure the authentic voice of the child is prioritised in this data, I have presented a collection of different representations of the co-researcher's experiences of play. This is to accommodate for the diverse range of co-researcher communication and interpretation abilities and preferences. In the below vignettes, stories directly from the child, conversation from the support network, and my own ethnographic observations have been used to create a narrative that reflects the children's emotional engagement with play and to take seriously the depth of their challenge, response and agency.

This approach takes inspiration from (Stafford, 2017a) who maintains that children are the expert-users of playspaces, and that their unique expression must be supported by their support network to communicate effectively what their experiences are. Given the constraints experienced in the research, it is no simple task of simply delivering unmediated output from the child co-researchers, but neither is it possible to reproduce their phenomenological experience. Therefore, I have chosen not to solely rely on the opinions of the co-researchers support network, but rather to enhance the expressions of the co-researchers through their support network's contributions and from my own field notes.

This can be summarised by the example of when I asked Melanie what her favourite part of Livvi's Place is. Her response was that "the swings" were the "best part", in particular the "basket swing". Her sister followed up this comment by explaining that Melanie once had a bad experience where she fell from an unrestrained swing seat. When I had asked Melanie's mother directly a few minutes earlier what Melanie's favourite place is, she explained to me that Melanie prefers things which she can do on her own, and that even though she enjoys

the swings a lot, they are unfortunately, a little too high off the ground for her to manage on her own.

Looking at all this information, we can see a number of opinions about what Melanie's preferences are. When reviewing this data using the holistic approach which I am using to construct and present the vignettes in this chapter, it is evident that while Melanie appreciates the independence of using equipment on her own, ultimately, she still thinks that the big basket swing is the best and the safest. Here Melanie's mother's input prioritises her independence, her sister's focuses on safety and risk, and most importantly, Melanie opinion is shaped by the fun she has.

Typically, in research about young children's experiences their own opinions are silenced and overridden by by-proxy research. Symptomatic of this approach is a dismissal of the importance of fun – an aspect of childhood experience which does not receive adequate attention in research. It is evident from the above example that without the input of the co-researcher the image created of Melanie's experience of play would be focused on risk assessment and capacity building, potentially without consideration of her enjoyment.

There have been significant challenges in representing the data. The above example shows the often conflicting nature of data, and also exhibits how it can be pieced together to create a 'whole story' of experience. The vignettes below are presented with this collaborative approach to data, and are accompanied by artistic representations images of the spaces and some examples of how the co-researchers interact with these spaces. This visual representation of the experiences of play has been chosen to maintain co-researcher anonymity, at their request, and to strengthen the narrative extracts which 'paint a picture' of play.

### *The Vignettes*

The vignettes represent three major types of spaces at Livvi's Place, passive, low-sensory, and high-sensory areas. They have been chosen to provide a diverse representation of geography, as well as depict how non-typical practices, behaviours, and experiences can significantly alter how a space is used, understood, and interacted with. This provides interesting insight which often contradicts mainstream reflections on spatial design and experiences of connection

from an adult ableist position, therefore reinforcing the importance of highlighting the co-researchers voice in the research.

The vignettes are arranged as:

- a low-sensory space – the sandpit
- a high-sensory space – the flying fox
- Passive spaces – paths and benches

### *The Maps*

The maps represent the data collected from the mapping exercise conducted with the co-researchers and their support network.

As outlined in chapter 4, this exercise was conducted in a flexible and tailored way to enable all co-researchers to participate in any way they could. This meant that the co-researchers were asked to contribute to the creation of the maps in a number of different ways including drawing images, writing words, verbally communicating, or the support-network communicating on their behalf. This data was then taken to create ‘heat maps’ which identified the locations and equipment in Livvi’s Place which provided positive experiences of play and belonging. Some of the triggering questions used to initiate these responses asked the co-researchers to identify places where something good happened, what their favourite place was and why, and the equipment which they like the best.

Below are the four ‘heat maps’ associated with each co-researcher. The areas which they identified as positive and fun are colour coded in pink for high-colour contrast to the map. The playspace map has also been faded to enable a stronger colour-contrast between the map background and the colour identifying the ‘good’ spaces.

Drawings and quotes taken from the mapping exercise have been inserted throughout the following section to illustrate some of the diverse ways in which the co-researchers contributed to the mapping exercise.

## The Vignettes

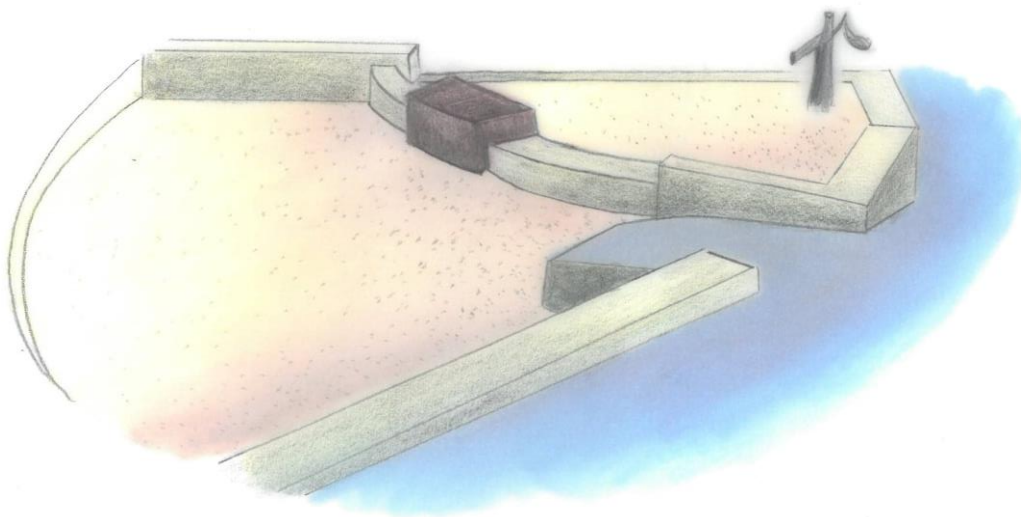
### *The Sandpit*

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*“Well, the sandpit... I don’t really like the sandpit. The last time I was here, the sand was a little too low. So that means that I couldn’t walk onto it.”*

*Aaron*

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*As I watch Melanie in the sandpit I notice that this is the first space which she is able to access and enjoy independently from her support network. The gap between the path and the sand is a little high, but she manages to get her walker down and her feet in the sand. I can sense a feeling of calm in MELANIE here, there's no older children running around or riding scooters. She is surrounded by children closer to her age who are interested in quieter play and interested in her.*

*Observation of Melanie*

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*“Sometimes when Ben’s playing, because he’s a bigger kid and there’s often littler kids in the sandpit there’s that, um, sometimes he can take their toys or they take his. This can lead to a lot of social challenges... which can be difficult”*

*Ben’s mother*

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*When the play is very physical Melanie can’t really keep up. So, that can be quite limiting in a playground environment, except when it’s a more quiet area like the sandpit or if the kid’s exceptionally patient”*

*Melanie’s mother*

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*"I think it's the whole sensory experience for Mia. There's no risk involved. For Mia, she doesn't like things that go really fast, she doesn't like lying backwards where's in the sand pit she can get that sensory experience. It really is sensory for her, from the time she was a toddler we've had a little sandpit at home... in the warmer months she would get in the sand and just lie in it and cover herself with sand and it's the Bene experience being here at Livvi's place"*

*Mia's mother*

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## *The Flying Fox*

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*Researcher: "Do you like the flying fox?"*

*Melanie: "I don't like it at the end."*

*Researcher: "Where it bumps?"*

*Melanie: "Yes, and I don't like it going so fast."*

*Melanie*

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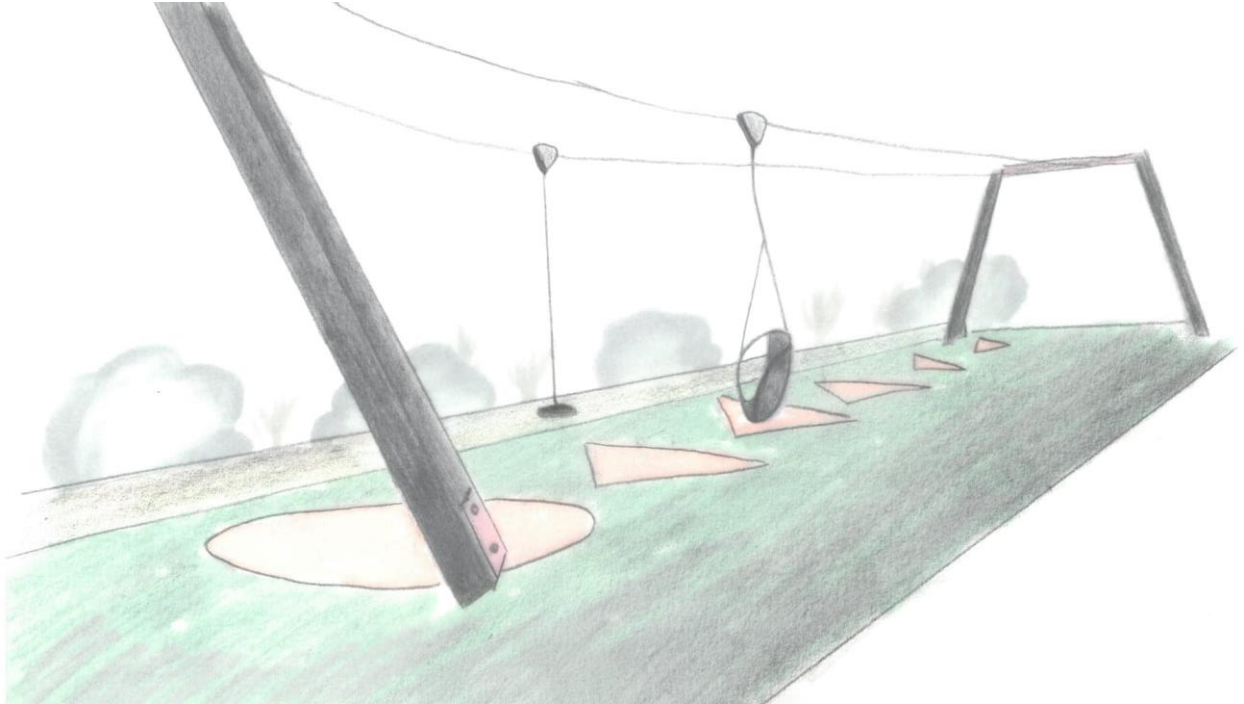
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*Mia leads me through the playground at an almost running pace. I notice that she follows lines of nature, walking from bush, to stick, to grass. She continues to lead me in circles around the playspace actively avoiding places where there are other children or fast-moving things. I reflect on MIA's mother's comment that she does not like the feeling of falling as we take a dramatic detour to avoid colliding with a young boy on the flying fox.*

*Observation of Mia*

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*It's hard for me too, because we have to lift him on there [the flying fox].  
We used to go to a lot of parks where you had to lift him to use equipment,  
which is a bit hard..."*

*Aaron's mother*

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*“He tends to go to thrill seeking things. So, it’ll be this [flying fox]... Like, he could be on that for ages with me pushing... It’s like the equivalent of a one hour OT session. When we first started going here [BEN] wasn’t so big on the flying fox, but now...”*

*Ben’s mother*

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### *The Paths and Benches*

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*After Ben had spent twenty minutes intensely engaged with the flying fox and the swing, it was clear that he needed a break. He first went into the tunnel for some space. When some children followed him in there making loud excited noises he left, preferring the quiet company of his mother and sister at the park benches.*

*Observation of Ben*

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*"Actually, you've got to walk down the path and there's a toilet block down there. But there's no exit there, so we've got to use that exit over there. And again, with kids who have mobility impairments, you want to try and limit walking as much as possible"*

*Melanie's mother*

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*When I first met Aaron, he asked if we had to go around the playspace. He would much rather stay in one spot as he was tired. He explained to me that he had done a lot of physical therapy the day before and it had exhausted him. He picked a quiet and shady area where we had a good view of Livvi's Place so that he could point to each area as he spoke about them.*

#### *Observation of Aaron*

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*"As we walked in there was a bunch of these spiky little bushes next to the seat. She stopped and reached in and was really enjoying playing with them for a while.*

*Mia's mother"*

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## The Maps

Mia



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*“when Mia’s in the sandpit surrounded by the other kids...it’s a really great opportunity to talk about disability with these kids. It’s the time where they can be moulded and learn the most.”*

*Mia’s mother*

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*Aaron*



*"I'd prefer to sit here and talk if that's ok? I'm a bit tired...we can see everything from here"*

*Aaron*

This Way up



Ben

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*"is that a Beyblade?"*

*"I have one of those too."*

*"Can yours go higher than this?"*

Ben

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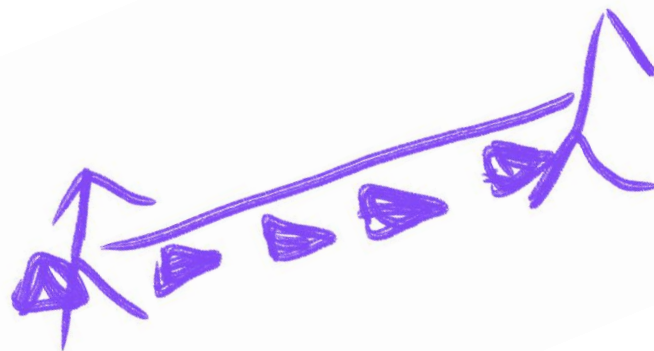
Melanie

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Can you push me very high?"

Melanie

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"I can't get up, can you help?"

Melanie

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## Conclusion

This chapter has shown the data co-created from the four child co-researchers and their support networks during interviews at Livvi's Place, Ryde. The intention of this research project, as well as its main challenge, was to effectively and authentically represent the lived experiences of the co-researchers, so to better understand the role which inclusive play has in their lives. The secondary intention of the project was to develop and trial new research methods which would facilitate the primary research goal in a conscientious and ethically sound way.

The data has been presented in two forms, the place-based vignettes and the maps, each representing the diverse experiences of play which the co-researchers have. The experience of working with a respondent group who have such varied communication and interpretation abilities was a difficult element to overcome and required a creative approach to the research development and the data presentation.

The choice of representing the data as place-based vignettes was to emphasize the vastly different experiences which can occur within the same place. In the data we can see that the co-researchers' experiences of a space were varied and affected by their past experiences, their physical ability, their communication and social ambitions, and the influence of their support networks. This information is then visually represented in the maps which show that each child has very different ideas of what makes a 'good' area for play and what 'good' play looks like. Both data representations have been paired with excerpts of the data to provide examples of the kind of responses given, and provide insight into how this was then visually represented in this chapter.

They allowed the communication of thematic aspects of play including risk, independence, fun, and adventure. From this, it is evident that while good design is facilitative of positive experiences of play, it is ultimately driven by social processes and community engagement. It has shown that while a space can be inclusively designed and have all the right structural elements, giving children the best opportunity to have inclusive play, it doesn't mean that all play experienced there will be inclusive.

## **Chapter 7: Making Sense of Inclusive Play, Inclusive Playspaces and Complicated Lives**

This research faced significant challenges in trying to work empathically and directly with the children as co-researchers while simultaneously respecting the diversity of their circumstances and recognising the empathy and engagement of the children's networks of support, care and advocacy and the commitment and difficulty faced by key policy and advocacy stakeholders. This chapter reflects on just what the data collected during the playspace explorations, participatory mapping exercises and interview processes might reveal about the what inclusive play looks and feels like for children with disabilities and how the field experience of doing the research has required some careful reflection on the issues raised in the literature (Chapter 3).

The reality experienced by the child co-researchers and their support networks in this project is that the world of inclusive play, childhood disability and public space is complex and messy. The research circumstances meant that the research collected only limited data, but even this limited data has provided a wealth of opportunity to think carefully and critically about research design and execution for the next phases of this research journey. In that sense, as a pilot for future PhD research, the research has been of value. But what has it revealed about just what the experience of Livvi's Place at Yamble Reserve in Ryde means for my co-researchers? This chapter walks through the key learnings of the research project, focusing on how those with messy lives can contribute as valid informers, how this data is interpreted, key observations, and an explanation of what it all might mean.

### **Disabled lives are messy**

Despite the careful planning involved, the nature of this complex co-researcher group meant that there was significant learning along the way. And despite the routine expectations of University research and assessment schedules, the lives of my co-researchers and their families refused to fit into predictable routines. Plans were made, but health, weather, medical appointments and carers' needs all disrupted those plans at various points. Ambitious recruitment targets were imagined, and invitations were issued through the networks of

Touched by Olivia, but some of those who responded initially found they were unable to participate after several attempts to schedule meetings at Livvi's Place.

As verbal communication was difficult for majority of the co-researchers, flexible research methods needed to accommodate effective communication of ideas and experiences by non-verbal means accessible to the co-researchers. The research design included a pilot phase, where the research materials were trialled for practicality and capacity to collect relevant data. This process allowed for refinement of the tools used in the research. It quickly became clear that the playspace map had to be an integral part of the research process, but making sure it was useable in the field caused delays.

Instances of medical emergencies, short-attention spans, and physical exhaustion interrupted the attempts to organise consistent and regular interviews at Livvi's Place. A key moment of insight was when I asked a parent "when would be a more appropriate time" to reschedule and they responded that they "could never know when would be a better time, this is just how our life is, we live it day-by-day". There were two examples of disinterest from the co-researchers which prevented the research process from being completed. This was, however, a valuable insight into the realities of the lives of children who have disabilities. The small glimpse I was given into the complicated lives of those who experience childhood disability, as well as their families and larger support networks, made it evident that these people could not be fit into a typical framework or schedule. Of those who were able to attend the scheduled meetings without the same level of difficulty, were only able to do so due to a complicated level of planning and organising which the support networks took on. Even siblings of the co-researchers carried much more responsibility than other children their age, being responsible for checking weather, UV range, appropriate parking, crowd expectations, and medications, to name a few.

## **Interpreting the Data**

The research collected several sorts of data. In the playspace explorations, the data included: conversations and other input from the co-researchers; comments by their support network; my own ethnographic observations; and drawings from the mapping exercise. While each data set was reviewed individually, the greater challenge proved to be in knitting all the data

together to provide a multidimensional representation of experience whilst prioritising the voice of the child over that of their support networks. Despite the intention of the research design, the voice of the co-researchers was not as strong as the verbal input from their support networks. This is typically what is utilised by research investigating the experiences of disabled children. The strength of the co-researchers, however, came through in the subtext of the data. It came through in the observations I made of their movements, interactions, and reactions to spaces and people. This was recorded in my fieldnotes. From this rich data I was able to draw out significantly more depth and understanding.

This atypical approach to data interpretation was strongly influenced by the analysis of rich text and ethnographic observation in anthropological studies (Ginsburg & Rapp, 2013). Phenomenological studies were also drawn upon to inform how expressions of experience can be woven into building meaning from experience. For example, reflecting on methods such as walking interviews (Evans & Jones, 2011; Hamm, 2015; Keinänen & Beck, 2017; Middleton, 2010; Ramsden, 2017; Warren, 2017), critical autoethnography (Allen-Collinson & Hockey, 2008; Grenier & Collins, 2016; Jackson & Mazzei, 2008; Tsalach, 2013) and phenomenological studies in social sciences (Casey, 1996; Kearney & Griffin, 2001; Krycka, 2006) pushed me much closer to attending to my own experience as a source of understanding.

The co-researchers had limited opportunities to engage with me in the playspace, and that limited my opportunities to engage with their preferred ways of presenting what was understood as 'the data' that would be interpreted in the thesis. The early challenge to think about what the data for this research would look like and how it would be interpreted (or even interpretable) have continued to challenge with the temptation to return to more conventional 'research-by-proxy' approaches to data collection.

## **Key observations**

Key observations need to be made from the co-researcher's experiences of play. It is easy to assume that research, even social research, is done in a kind of clinical vacuum where emotions such as boredom, frustration, disinterest, fear, distraction or dislike don't come into play. From the observations in this research it is clear that the co-researcher's emotions and

interest, or lack thereof has played a huge role in contributing valuable insights. In fact, what became the most valuable and robust aspect of the research process was the challenges faced by both me and my co-researchers and their support networks. The emotional barriers, the medical emergencies, and apologetic withdrawals. These all show what the experience of childhood disability looks like in its routine tension “between sorrow and joy” (Kearney & Griffin, 2001) better than any perfectly run study without complications. It shows the humanity in the experience of being human and the challenges which come along with it.

From this research project, the key takeaway for me, as a researcher, is that we can never be fully prepared when we’re working with the complicated and messy reality of people’s lives. The best that can be done is to be open to their struggles, and do our best to facilitate the expression of their reality. This was the key motivation to creating flexibility in the research design so that forms of expression not often catered to in research was able to shine through.

What is clear from the data is that whilst well designed spaces which are considerate of differences in ability can facilitate positive experiences of play for young children who have disabilities, the biggest driving factor for these positive experiences is the social processes of engagement, education, and exposure. This came through the data from the stories relayed by the co-researchers and their support networks which praised the positive influence of the environment of Livvi’s Place. It is also abundantly clear, however, that an accessible and inclusive physical playspace, by itself, is not sufficient to address all the needs and challenges of even this small cohort of children with disabilities and their networks.

Another key insight from the co-researchers was that their disabilities would have a long and profound impact upon their lives, but that this impact doesn’t have to be negative if they are given the right environmental and social conditions to thrive. This came across in the hope for the future which the co-researchers showed. The relentlessly positive attitude of children goes unrivalled and creates the most wonderful opportunities for learning and positive change for the future of our inclusive communities. Their exuberance and delight in having access to inclusive play shone through as hugely important to their sense of self and joy in living. Children with disabilities want to be a part of the change which they want to see in the world. They are insightful beyond measure and an honest reflection of the state which we are in as a community. Their experience echoes a long thread of advocacy by disability rights

campaigners, including the first Disability Discrimination Commissioner, who is quoted as saying:

*... disabled people didn't want sympathy, let alone pity or charity; they wanted their human rights* (Elizabeth Hastings in the early-1980s quoted in Henningham, 2014)

To this researcher, at least, it seems about time that children with disabilities like my co-researchers become the centre of research into their own experiences.

## **What it all might mean**

This research commenced with recognition that young children with disabilities are often not just excluded from playspaces, but also neglected in academic research. The implications of this is that a limited understanding of their experiences, needs, and expectations is drawn into wider social discourses around policies, resources and opportunities. Subsequently, the policy targets aimed toward children with disabilities, even when they are informed by research evidence, often fail to address their real-world experiences, aspirations and needs. The existing research on children with disabilities, while attempting to bridge this knowledge gap, is often developed from a position of adultist ableism. For example, very few research projects place value on the voice of the child (Stafford, 2017b), preferring to consult the care network of the child – a process Stafford called researching by-proxy. This project endeavoured to respond to Stafford's call to do better than the disability studies disciplinary standard of by-proxy research by strongly saying that we can do better.

This research has explored varied ways in which the co-researchers contributed to the research with validity and substance. This has recognised that each co-researcher has their own unique and well-developed means of communication. Given that 'alternative' forms of communication emerge out of necessity, for example a child being non-verbal and therefore choosing to communicate through a combination of pointing and Makaton, it is imperative that they be listened to in adaptive and creative ways as they, in turn, have had to be adaptive and creative to communicate. This is particularly relevant for research with people who have disabilities, as the 'acceptable' form of acquiring information in research is often funnelled through the parameters of ableist research, meaning that verbal and articulate communication is preferred and respected, whilst other means are often not. There is

insufficient recognition of varying and diverse ways of communication of people who have disabilities within the study of people who have disabilities.

A central theme of this research is the acceptance of simply learning to live, work and play with diversity. It has played a large role in directing the ambitions and creative direction of the thesis. In fact, a missing recognition of diversity in our community, research, and policies is what inspired this research to begin with. The secondary motivation behind this thesis is to use the developed research methods to facilitate the learning and understanding of the academic community on the lived experiences of children with disabilities. The focus is on how children who have disabilities experience play, and specifically what factors contribute to successful, or 'fun' play.

This section outlines some of the key conclusions from this MRes thesis as it pertains to the key research questions identified at the beginning. This means that we will take a journey back to the point of departure for this research project and address the ways in which our understanding has now changed as a result of this research.

Realising the extent to which children with disabilities are a missing link in research about them has brought a new-found sense that recognition of implicit and undeclared ableist positionality in research is more dominant and strongly embedded than is widely recognised. The continual endorsement of research by-proxy on the experiences and lives of people with disabilities exhibits a carelessness which can only be described as Janus-faced. Without the enthusiastic participation of people with disabilities in research about them, true recognition of them as active and powerful agents in their own lives cannot be achieved. In this way the authority of people with disabilities is recognised by propping up their champions and advocates on their behalf, however, they are not themselves enabled. This is because it is easier to take easily interpretable by-proxy data which intellectualises disability rather than support the expression of user-experts in research practices. The inclusion of children with disabilities in research about them is considered in the same way within this thesis, however with an added layer of complexity. Children are often further disendorsed as capable of representing disabled experience due to their age, and therefore, their perceived capacity to articulate their experiences and needs. But when it comes to the experience of play, they are exactly the people we need to hear from. If facilitating people with disabilities to contribute



to the body of knowledge on their experiences is considered a challenging research endeavour, then researching with children with disabilities certainly requires more sensitivity to our position and responsibility as researchers.

At the outset of this research project this contradictory dynamic of research with children who have disabilities was recognised. Now, upon reflection it is evident that misguided research practices do much more than limit the knowledge gained from academic research. It depoliticises the legitimacy of children with disabilities as members of our community and denies their capacity, or right, to have a voice and influence. Inverting this way of thinking about disabled children's capacity to contribute in research therefore provides the opportunity to engage at much deeper levels and with greater understanding of what the needs of these young people are from the community, from research, and from the policies which they inform.



## Chapter 8: Conclusions

This research set out to understand how children with disabilities experienced play and what made it inclusive for them. Specifically, it addressed three questions:

1. In what ways can children's experience of play be captured using participatory methods,
2. What are children's experience of inclusive play spaces?
3. What have Local and State Government responses been to the challenges which children with disabilities face when engaging in play?

This research made some progress towards answering those questions, but there has also been much learning along the research journey. In particular, the need to attend to both my co-researchers and my own experiences has been crucial, and recognising that the research is always undertaken in a changing policy, academic and practical setting.

The lasting impact of the research journey is the joy of working with my co-researchers, but the disappointment of realising that I have not adequately addressed the gap that I identified in the research literature as the tendency to do 'research-by-proxy' (Stafford 2107b). After going through this research process, it is now clear that the challenges which often turn researchers toward a by-proxy style of research are the exact hurdles which became my biggest challenges, and a task not yet fully accomplished.

This concluding chapter discusses methodological lessons to be drawn from the research, reviews the research findings, revisits the field-based research experience and considers the implications for future research, both in terms of the wider research agenda for inclusive playspaces and my personal research journey towards doctoral research.

### Research Design and Data Collection

Working with my co-researchers and their diverse experiences and communication abilities was a challenging experience. The main challenge was to develop research methods to collect data in ways which would provide each co-researcher with a fair opportunity to use their strengths to communicate their experiences. The project was a pilot study designed to facilitate the development and trial of suitable research methods which would give young children with disabilities the opportunity to shape the research and participate in it as a

source of authority and expertise. To reinforce the authority of the child, their typical social position of less-than-adult was challenged as they became 'co-researchers' in the project.

The University's HREC application process refined the research methods. The ethics application triggered a number of flags for the Ethics Committee – working with children, working with participants with disabilities, working in the field. Framing the approach as 'ethics as first method' (Howitt, 2011), I worked with my supervisor to shape an approach that would be fair and consistent amongst all co-researchers. As the MRes project is also intended to frame future PhD research, we also hoped to create a research design which would not simply meet the HREC standards, and allow the co-researchers to participate according to their strengths, but would also be transferable and scalable to future research. The research design sought to place high importance on the co-researchers' experience, and to ensure attention was paid directly to their input, as well as inviting strong participation from their networks of love, care and support and also inviting critical engagement from a wider network of stakeholders. As explained in chapter four the methodologies were, in-part, shaped around gathering data which would answer the research questions. This meant that general interview questions were created and adapted to each co-researcher as needed, therefore, not sticking to a 'script' of any nature and allowing a more free-flowing conversation style response from the co-researchers and their support networks.

## **What the children's data told me**

From the development and trial of research methods it is clear that researching with this demographic is still a challenging task. However, with the progress made within this research project, there is now a tested approach which has provided insight into the experience of researching with young children who have disabilities. It became evident during the fieldwork in Livvi's Place that, while the research methods were developed to be flexible in both communication and the ways they can be responded to, nothing can prepare the researcher for the challenges which are faced during the interviews. It also brought to light how often the research participants' mood is not considered in research design. Especially when working with children, the environment, the crowds, or even the personality of the researcher can have huge impacts on the success of data-creation. This was experienced during one of the research method trials when the young volunteer was disinterested in the playspace and was

more interested in encouraging his family to go home. No doubt, this presents greater research challenges than most researchers are prepared for. But, it also presents wonderful opportunities to get a glimpse into the lifestyles and challenges of the research participants.

The positionality of the co-researchers in this research has contributed so strongly within this thesis, and played a large role in directing the research agenda, data collection, and data representation and the outcomes of this approach to research represent more than a new approach to researching with children who have experiences of disability. They represent what can be achieved when children's right to participate is encouraged and enabled. What I have found throughout the process of researching with the co-researchers is that they have an unanticipated level of self-awareness and understanding. This shone light on my own prejudices which were present at the beginning of this project. Assumptions that are reflected in the broader academic community. Having these expectations challenged forced this research project to be reconsidered at several junctures, continually pushing me for greater flexibility and openness.

## **Tensions between data sources**

One of the issues that has pushed my thinking about the data is the tension between the direct input from my co-researchers and the input from their networks of support and advocacy. Given the challenges of parenting and caring across the sector (Kearney & Griffin, 2001) I certainly don't want to be mistaken as thinking that parents, carers and advocates deliberately misrepresent or misunderstand the experience, needs and concerns of the children they love and care for, but it is in this uncomfortable in-between space that I think there is much to be learned, particularly about play. Play is about direct experience – not about supporting a child to meet a particular developmental goal, or to ensure a Council authority is implementing this or that specific formulaic guideline. For example, in Melanie's case, she was able to voice her own priorities of having fun which at times seemed to be in direct opposition to that of her support network's concerns. This is exemplary of the tensions which became evident in the data from the research (chapter 6), representing the intersection of advocacy and self-advocacy.

Whatever the approach to research with children with disabilities, it is imperative, as recognised in Chapter 7, that they be “listened to in adaptive and creative ways as they, in turn, have had to be adaptive and creative to communicate”.

## **Issues from the literature**

The research methods trialled in this MRes project have done exactly that, they have facilitated the communication of experience, allowing children who have disabilities the opportunity to change the way they are represented and engaged with in research, independently and with full recognition of their agency. The literature review prepared for the research identified a dominant approach that Stafford (2017) referred to as ‘research by-proxy’, which avoided engaging directly with children with disabilities and took input from carers, families and advocates as a proxy for that input.

In the literature, it was recognised that for advocates of UD there was a large focus on technical design issues rather than actions “focused on education and creating opportunities for people with disabilities to enjoy full citizenship rights” (Henningham 2014). This position risks avoiding engaging with the lived experience of children such as my co-researchers, as occurs with by-proxy research, and represents a mismatch of designers ambitions and users’ needs. As discussed in Chapter 7. “the biggest driving factor for these positive experiences is the social processes of engagement, education, and exposure”.

The emerging literature on geographies of care (Williams, 2016, 2018) opens avenues for research that is much more readily engaged with the experiential rather than design elements. I recognise that this path is deserving of its own in-depth investigation to better understand how geographies of care support and nurture a child’s phenomenological experiences of inclusive play. This research, however, does not take on this task.

The key conclusion from the secondary challenge of understanding the experiences of play which children with disabilities had in Livvi’s Place focus around the facilitative nature of considerate space. It is clear that whilst considerate Universal Design is facilitative of good experiences of play, it is not sufficient to ensure inclusive play as the difference is made by the social processes of openness to difference and learning.

## **Issues from the fieldwork**

The relationship between local government, disability advocates and citizens with disabilities is often a tense and awkward one. Disability services have been radically recontextualised by the NDIS and local government support of public spaces. Such is the case for inclusive playspaces as their existence is always conditional on local governments' financial situations – which is often determined by budget allocations from the states as much as their own strengths and weaknesses. Issues of insurance, maintenance and useability all affect the way local councillors and council staff respond to the needs of disabled citizens, including children whose invisibility is exacerbated by their lack of voting power in local and state elections. One result of this is that engagement at the community level is difficult and often contested. Systemic barriers and uninformed attitudes need commitment and leadership to transform into experiences of exclusion for people with disabilities into recognition of play as a right for all children. For local government, where administrative complexity already challenges their capacity to engage, the immediate problem becomes not how to deliver excellence, but how to comply with new guidelines, changing community expectations, and changed budget settings. This makes local government a difficult partner for advocacy groups in pursuing participation in NSW's progressive model for disability inclusion.

## **Next steps**

This MRes research project was designed to create a foundation for a future PhD both in terms of research interests and methodological development. There has been a significant amount of learning throughout this research process which had shaped the direction of my intended future research.

The scalability of the developed and trialled research methods is limited. It is clear that they are not suitable for large groups of respondents. They do, however, provide the opportunity to get to know a little better the intersection of advocacy and self-advocacy. A way in which these research methods could be improved is to have longer engagement with the co-researchers and their families. This was the main limitation of undertaking a one-year MRes research project. I was unable to have multiple visits and conversations with the co-

researchers which I believe would strengthen the opportunities to learn from their experiences.

Having come to the end of this research journey, I can safely say that if I were to start over, I would not have begun in the same place. The methodological standpoint as well as the research groundwork I laid in the literature review directed the study in ways that I can only see now that I have come to the end. The research openings which I encountered along the way (geographies of care, for example) have shown me how my future research can lead from the point of closure of this project.



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# Appendices

## Appendix 1: Ethics Approval

Office of the Deputy Vice-Chancellor  
(Research)

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21 December 2017

Dear Professor Howitt

**Reference No:** 5201701088

**Title:** *Valuing Inclusive Play Spaces: Disabled Children and their Occupation*

Thank you for submitting the above application for ethical and scientific review. Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)) considered your application.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted by Ms Ebony Appel under the supervision of Professor Richard Howitt.

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated May 2015) (the *National Statement*).

### **Standard Conditions of Approval:**

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email [ethics.secretariat@mq.edu.au](mailto:ethics.secretariat@mq.edu.au)

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

[http://www.research.mq.edu.au/for/researchers/how\\_to\\_obtain\\_ethics\\_approval/human\\_research\\_ethics](http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics)

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely



**Dr Karolyn White**

Director, Research Ethics & Integrity,

Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

**Details of this approval are as follows:**

**Approval Date:** 5 December 2017

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form		Received 01/11/2017
Response addressing the issues raised by the HREC		Received 02/12/2017
Participant Information and Consent Form	2	01/12/2017
Interview questions	1	01/11/2017

**\*If the document has no version date listed one will be created for you. Please ensure the footer of these documents are updated to include this version date to ensure ongoing version control.**

**From:** Ethics Secretariat  
**Sent:** Tuesday, 17 April 2018 1:55 PM  
**To:** Richie Howitt  
**Cc:** Ebony Appel (HDR)  
**Subject:** Re: Reference No: 5201701088 - Amendment request:

Dear Richie & Ebony

The Executive approved your amendment request at its meeting today. Please accept this email as notification of approval.

Kind regards  
Fran

**Ethics Secretariat**  
**Research Services** | Level 3, CSC Building  
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## Appendix 2: Trialled Maps

