Selling the artwork, not the label: exploring the experiences of artists with cognitive impairment towards professional recognition

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Dissertation submitted in partial fulfilment of the requirements
for the Graduate Diploma in Research Methods

Disability and Community Inclusion Unit
College of Nursing and Health Sciences
Flinders University
Adelaide, Australia
September 2019

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Declaration

I hereby declare that this research dissertation is my own original work; and all the sources are accurately reported and acknowledged; and it does not include any material previously published or written by another person except where due reference is made in the text; and does not include any material previously submitted by me for a degree or diploma in any university.

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Date: 20/06/2019

Acknowledgments

I would first like to thank my supervisor, Associate Professor Caroline Ellison, who opened a door for me to explore invaluable experiences of learning, and understanding what inclusion means in our society; she provided me with direction and encouragement throughout the writing of this dissertation even after she departed Flinders University.

I would also thank my second supervisor, Ms Margaret (Peggy) Josephine Essl, who provided me with a great deal of support and valuable feedback throughout the process of writing, even during her annual leave.

I would like to thank Editor, Philip Ellison BEd (Adel), GradDipTESOL (UniSA), GradCertDisStud (Flinders) who provided copyediting and proofreading and formatting services, according to the guidelines laid out in the Australian national 'Guidelines for editing research theses'.

I would like to acknowledge all the participants of the interviews because the research could not have been completed without their willingness to participate in this project. I would like to thank all of them for sharing their experiences, beliefs, aspirations and vision.

Most of all, I would like to thank my husband, Seong Kyu, who always believes in me and my potential to pursue my aspiration. I would not have been able to complete this thesis without unconditional love and support from him.

Finally, I would like to thank my only daughter, Joanne, who has been my muse and inspiration. She has taught me that verbal language is not the only communication, but we can communicate without a word when we open our heart.

Contents

List of Tables and Figures

Tables

Figures

Abstract

An aspiration of individuals with cognitive impairment who participate in art is to have their art practice viewed as a professional art career, not as 'art therapy', within community-based art organisations across the world. Art has been recognised as an excellent and effective medium for individuals with cognitive impairment, especially for those who need an alternative mode of communication, to express their thoughts and inner world. The functions of art are categorised into four groupings; 'therapeutic art', 'recreational art', 'disability art' and 'outsider art', depending on the pursuit of art practice of individuals with cognitive impairment. However, those individuals with cognitive impairment who have been seriously involved in art practice, have passion and desire to develop their art practice more professionally as an employment opportunity. They also do not wish to be recognised as artists with cognitive impairment but as professional artists, without the label 'disability', in mainstream art and in the public space.

This current study explored what challenges and enablers artists with cognitive impairment have experienced to develop their art career as a professional artist, using semi-structured interviews with caregivers and art facilitators, including art staff and mentors who have closely supported two artists with cognitive impairment. Due to significant limitations such as time, resources and funding, direct interviews with artists with cognitive impairment were not feasible. Therefore, this study undertook a 'proxy' intervention interview approach to explore the lives and experiences of the artists with cognitive impairment, through the perspectives of caregivers and art staff who have already established close relationships with the artists. This current research study was conducted in two art organisations in Australia and two art organisations in South Korea. The findings of the research are significant to draw an overview of the challenges and the enablers under four main thematic headings; 'individual', 'systemic', 'societal' and 'professional'. The details of the findings indicate practical and functional elements, such as 'effective mentorship programs'; 'artist agreement'; 'partnership or collaboration with commercial companies'; and 'complexity of financial management between the government pension and extra income if any is earned'. This study also found some social and cultural differences in the responses between Australian participants and Korean participants. The most significant finding of the study is the importance of changing the public perspective of artists with cognitive impairment from 'incapable' to 'capable', as this can positively influence society and enhance opportunities for artists with cognitive impairment to pursue art professionally.

Chapter 1
Introduction

1.1 Background of the study

This study explored the experiences of individual artists with cognitive impairment through the perspectives of the caregivers and art staff who have supported the artists in establishing their artistic careers as professionals. Art is an activity that historically has been part of human endeavour as an early means of communication (Whitley, 2009; Oloidi, 2016). Art can be an expression of an individual's perceptions and world view through using creativity as a form of non-verbal language for individuals with cognitive impairment including those living with Autism Spectrum Disorder (ASD), intellectual and cognitive disabilities. This includes individuals with cognitive disability who may have difficulties with verbal communication. The visual means of expression for some individuals with cognitive disability provides an opportunity for them to engage and a means for them to interpret the world around them in creative ways (Grandin, 2016 cited in Mullin, 2016; Roth, 2018; Wexler & Derby, 2015). However, the literature of published experiences of individuals with cognitive impairments suggests that they may not be able to achieve recognition as a professional artist because of being labelled 'incapable' by the general public or the mainstream art establishment due to their disability (Grandin, 2009; Wexler & Derby, 2015).

Art has contributed to the development of the disability movement as a means of understanding the lived experience and perceptions of disability by empowering people with disabilities to take control of their own representation through creative expression (Solvang, 2012; Sandahl, 2018; Chandler, 2018; Newsinger & Green, 2016). Art plays various roles in the lives of individuals with cognitive and other disability as a means of improving their well-being and social participation (Solvang, 2012; Sandahl, 2018; Evans et al., 2017; Darragh et al., 2015; Katz, 1996; Roth, 2018). Art can also provide individuals with disability the experience of living positive social roles through participating in creative activities, such as visual arts, music and performing arts (Darragh et al. 2015; Kapetas 2007; Lynch and Allan 2007; Matarasso 1997; Rossman and Schlatteer 2008 cited Evans et al., 2017; Roth, 2018; Vick & Sexton-Radek, 2008).

The participation of individuals with disabilities in creative art activities is presented in the literature in two different categories; 'disability art' and 'disability and art' (Solvang, 2012; 2018; Newsinger & Green, 2016; Richard et al., 2019). These terms have distinctively different interpretations and meaning. Solvang (2012) asserts that "disability art is art informed by the disability experience and created by disabled people" (p.179), whereas the term of 'disability and art' suggests art therapy

and outsider art. Solvang (2012, 2018) describes art therapy as being framed within the medical model with two primary purposes: to provide treatment through art activities based on psychiatric theories; and to create socially valued practices for people with disabilities. Outsider art is defined as artwork made by people who are not part of any art institution or any art establishment, which is often framed and facilitated by art collectors (Solvang, 2012; Wexler & Derby, 2015). Examples of outsider art include indigenous art and artwork of individuals with mental illness who are not formally trained to be artists (Wexler & Derby, 2015; Boyce, 2012; Cachia, 2014; Reed et al., 2015; Nyqvist & Stjerna, 2017).

The different interpretations of 'disability art' and 'disability and art' can contribute to some misconceptions and/or discriminative practices by limiting the value and view of artists with disability to mainly 'amateur' and 'community arts' status (Solvang, 2012; Sandahl, 2018; Nyqvist & Stjerna, 2017). These concepts strongly associate art with therapy, consequently leaving artists with disabilities to fight for opportunities for capacity building, skill development and professional recognition, rather than being limited to 'patients' or artists with a hobby (Solvang, 2012). According to Sandahl (2018), the lived disability experience can be a great 'asset' which can be expressed and developed in new ways of understanding disability. However, in reverse, the label, diagnosis and experience of disability could be a barrier to entering the mainstream art establishment and to achieving recognition as an artist in the same way non-disabled artists are recognised (Sandahl, 2018; Nyqvist & Stjerna, 2017). Solvang (2012) argues that "disability is culturally devalued" (p.183). Accordingly, when artists with disabilities attempt to enter the mainstream art establishment, the expectation for them is higher than that expected of artists who do not identify as having a disability. Additionally, the artists with disability are expected to do something not linked to disability (Sandahl, 2018). Sandahl (2018) also points out that artists with disabilities tend to succeed only when they show extraordinary talents because of the higher expectations placed on them. Artists with disabilities often experience challenges and discrimination around recognition of their professionalism in the mainstream art establishment (Sandahl, 2018; Solvang, 2012; Boeltzig et al., 2009; Nyqvist & Stjerna, 2017; Newsinger & Green, 2016). They may also struggle by being expected to position themselves as belonging to either disability art or the mainstream art establishment regarding the purpose of their artwork (Solvang. 2012; 2018; Wexler & Derby, 2015; Boyce, 2012; Cachia, 2014).

Case studies of living artists with cognitive disability provide additional insight into why it is hard to be recognised as a professional artist by the mainstream art establishment when a person identifies as living with cognitive impairment. The negative social image of viewing artists with cognitive

impairment as 'incapable' and 'inadequate' in society tends to devalue their achievement and limit their opportunities and engagement to stereotypical roles and expectations (Barnes 2003 cited in Darragh et al., 2015; Wexler & Derby, 2015; Richard et al., 2019). The disability service model along with the continued therapeutic perspectives around the medical model interfere with creating opportunities for people with disability to access non-disability-specific art services; funding; capacity building; and creating artistic settings and contexts for artists with disabilities to develop their careers beyond leisure, therapy, and a hobby, to a professional level (Evans et al., 2017; Darragh et al., 2015; Newsinger & Green, 2016). The artistic capabilities of artists with disabilities must be assessed without the bias of looking at potential limitations of any physical, cognitive or mental impairments. When artists with cognitive impairment demonstrate artistic capabilities, they should have opportunities to develop their artistic careers and be accepted in the mainstream art establishment without the label of disability, and the associated assumptions that their engagement is amateur or therapeutic (Darragh et al., 2015; Sandahl 2018; Solvang, 2012; Nyqvist & Stjerna, 2017; Vick & Sexton-Radek, 2008; Newsinger & Green, 2016).

Currently, there is a considerable amount of published research around therapeutic and recreational art activities for people with disabilities (Rostron, 2010; Richardson, 2015, 2018; Onyx et al., 2018; Malchiodi, 2003; Evans et al., 2017; Alter-Muri, 2017; Katz, 1996), but there is a paucity of research on artists with disabilities and their contribution to the art community in terms of engagement and economic impacts (Reeves, 2002 cited in Onyx et al., 2018; Vick & Sexton-Radek, 2008). One of the significant conditions of being recognised as a professional artist is the ability to gain financial benefits from the sale of artwork (Bain, 2005). However, Bain (2015) argues that it is difficult for artists who lack communication and social skills to establish the necessary recognition in the art world to be adequately compensated both financially and socially for their artwork. Artists with cognitive impairment who have difficulties with communication and social interactions may need a connector, a producer or a mentor to access the art world and to communicate with the public audience and industry stakeholders (Hayashi, 2008; Bain, 2015; Reed et al., 2015). This current study explored, through case studies, if having a mentor, supporter, carer or a family member who could create a bridge between the artist with complex communication needs and the art world, is effective and, if so, what characteristics facilitate and maintain achievement of professional artist status for individuals with cognitive impairment.

1.2 Significance and aims of the study

This current study aimed to explore the experience of three existing artists with cognitive impairment who had been participating in creative productions as serious leisure as defined by Stebbins (Stebbins & Cohen-Gewerc, 2013). It also included the perspectives of key supporters and other facilitators for the artists with cognitive impairment. The aim was to understand and identify the art practices that support and/or hinder engagement in serious leisure or professional artistic activities that result in capacity building, economic participation or recognition by the mainstream art establishment. It was anticipated that results would provide insight into current environmental settings, contexts, supports and social perception towards those artists as well as elucidate the processes, strategies and approaches that facilitate achievement of participation and recognition as a professional artist. The intent was to focus on the challenges, enablers, supporters and successes as an artist that in-depth case studies could provide and therefore contribute to the body of evidence to guide the careers of artists with cognitive impairment. In addition, this study aimed to provide evidence that individual artists with cognitive disability could, and have, achieved significant progress towards recognition as professional artists. It explored themes around effective strategies and environmental conditions including funding, personal assistance, environment, peers, context, access to specific art studios or incubator settings or community settings through the development of three case studies. Wolfensberger (2011) emphasised 'enhancement of competency' to create socially valued roles and quality of life conditions. Artists with cognitive impairment need appropriate conditions, including environmental settings and supports, to encourage the development of their artistic capabilities. This could assist them to participate in socially valued roles which in turn was reported to be linked to an increased likelihood they experienced a quality life (see Appendix 1). The case studies of artists with cognitive impairment are important as they reflect the reality of being an artist with disability in the 21st century at the point in time of the ratification by many countries of the United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). Findings of this current study provided an opportunity to explore and consider how to improve existing service models, service delivery, social perceptions and artistic support structures for the development of a mainstream art career for artists with cognitive impairment.

1.3 Focus of the study

This current research aimed to focus on developing in-depth case studies for three artists with cognitive impairment currently developing professional careers as artists. This was done in order to

identify and understand, and also included the perspectives of key supporters and artistic facilitators of the artists:

1. Challenges around access to artistic supports such as: an art studio; space and context; artistic peers; capacity building and developing technical artistic skills; mentoring; and peer review, creating art with guidance, and/or building a recognised connection to the mainstream art establishment.

2. Enablers for artists with cognitive impairment who support artistic aspirations to a professional career level such as: producers; supporters; mentors or members of the community; systemic scaffolders; and social or community support.

1.4 Nomenclature

For the purpose of highlighting the artists with different cognitive conditions involved in this current study, the researcher applied the following nomenclature. Artists with Autism Spectrum Disorder (ASD), intellectual, or cognitive disabilities are referred to as 'the artists' or 'artists with cognitive impairment' unless otherwise specified. Nominated significant others, carers, families and art staff members are referred to by their role (i.e. significant other, parents, carer, mentor, art director or art supporter).

Art galleries, art institutions and design or art related industries in the mainstream of society are referred to as 'the mainstream art establishment' unless otherwise specified.

1.5 Structure of the dissertation

The following chapters are included in this dissertation:

1.5.1 Chapter 2 Literature review

Chapter 2 is a review of the literature on disability art and social role theory. This chapter looks into the individual meanings and social roles of art in disability. It mainly focuses on the impacts of creative activities for individuals living with cognitive impairment. The literature review considers the long-term gap in existing knowledge and social phenomenon of recognising and enabling artists living with cognitive impairment in the mainstream art establishment.

1.5.2 Chapter 3 Methods

Chapter 3 explains the research methods, design, ethical considerations and the process of data collection, analysis and evaluation based on the research questions and objectives.

1.5.3 Chapter 4 Results

Chapter 4 includes a summary of the research including information on the research participants, and the description of the case studies based on the analysis, evaluation and synthesis.

1.5.4 Chapter 5 Discussion and conclusion

Chapter 5 discusses the main objectives of the research study through exploring the case studies, and it makes suggestions for the direction of future research as a conclusion.

Chapter 2
Literature review

2.1 Art and disability

2.1.1 Art definition

What is art? Defining the nature of 'art' has been a long-standing question for decades, and many scholars have been searching for an answer to underpin the fundamental concept of art (Fokt, 2013, 2017; Monseré, 2016; Currie, 2010; Davies, 1997). Philosophers of art define art as a 'normative project' (Monseré, 2016, p.256). However, depending on psychological, philosophical or cultural perspectives and different political and social circumstances, the concept of art definition has been differently interpreted (Fokt, 2017; Currie, 2010; Monseré, 2016). The anti-essentialist, Danto's Brillo Box argues that "art should be understood as always relative to a cultural context… no general definition of art is possible" (Kennick, 1958, p.324 cited in Fokt, 2017, p.408). Nonetheless, many theorists still attempt to find a way to define the nature of art (Currie, 2010; Fokt, 2013).

Fokt (2013) claims that George Dickie's institutional definition of art is one of the most attractive theories for discussion and critique because its definition implies that an authoritative group in the art world gets to decide what is art or not. The first version of the institutional definition classifies "a work of art in the classificatory is an artefact, a set of the aspects of which has had conferred upon it the status of candidate for appreciation by some person or persons acting on behalf of a certain social institution (the art world)" (Dickie, 1974, p.34 cited in Fokt, 2013, p.641). This institutional concept of defining art raises a critical issue because justifying art by the authoritative group of the art world is not reasonable, and doubtful without any subjective nor objective guidelines (Fokt, 2013). After taking into consideration the multiple problems raised, the institutional definition states that "a work of art is an artefact of a kind created to be presented to an artworld public" (Dickie, 2000, p.94-96; Dickie, 1997, p.80 cited in Fokt, 2013, p.641). This concept of the institutional definition seems to powerfully influence the legitimatisation of the status of an artist accepted as a member of the art world, or not, in the mainstream art establishment. Regardless, Gaut's cluster theory highlights that the term 'art' includes that "possessing positive aesthetic properties", "being expressive of emotion", "formally complicated", "belonging to an established artistic form", and "being the product of an intention to make a work of art" (Gaut, 2000, p.28 cited in Fokt, 2013, p.646). Fokt (2017) also claims that it is not the concept of 'art' that changes over time, but the art world, in terms of changing contexts and different levels of competence that people have. Currie (2010) suggests that the way of thinking about the nature of art should be different according to

different circumstances; accordingly, the art world should consider changes to creative and artistic expression.

2.1.2 Disability and art

Art has played a critical role in disability. Depending on the roles of art for purportedly different outcomes, functions of art can be varied in disability. Solvang (2018) proposes "four ways of understanding art and disability therapy; outsider art; disability art; and disability aesthetics" (p.238). These four aspects can be explained in two significant ways: art as a therapeutic tool to improve individual and social well-being of people with disabilities; and art as an expressive tool to promote an understanding of disability experiences or self-identity as an individual living with a disability (Solvang, 2012, 2018; Sandahl, 2018; Hackett et al., 2017; Rice et al., 2015; Grant, 2014). Medical perception considers art as a medium to understand the behavioural and psychological aspects of clients or patients through the process of assessment, planning, implementation and evaluation based on medical model theory (Malchiodi, 2003; Alter-Muri, 2017; Gunn and Peterson 1978; Robertson and Long 2008; Stumbo and Wardlaw 2011 cited Evans et al., 2017). Therapeutic art refers to participants in art intervention as a 'patient' or 'client', which terms also become a label of stigma for artists with a disability who want to be recognised as a professional (Solvang, 2012; Sandahl, 2018; Richardson, 2016; Rostron, 2010; Ludwig, 2012; Rice et al., 2015).

Art in terms of leisure or recreational activities provides opportunities to improve individual well-being including social interaction and communication skills, but it also creates a positive environment of socially valued roles for individuals with disabilities to be more productive through creative activities (Evans et al., 2017; Darragh et al., 2016; Luzzatto et al., 2017; Chandler et al., 2018). Transitioning from therapeutic art intervention to recreational art is an essential course of action for individuals with disabilities who intend to participate in creative art more independently (Evans et al., 2017). Stebbins and Cohen-Gewerc (2013) describe that through a process of self-development and leisure, individuals can unfold their unique individuality to discover various dimensions of individuals, which could lead to artistic creation. Participation in art creation as a serious leisure endeavour also encourages individuals with disabilities to gain 'self-satisfaction', 'self-enrichment', 'self-expression', 'feeling of accomplishment' and 'social interaction', similar to the benefits gained from employment (Stebbins, 2007 cited in Evans et al., 2017; Chandler et al., 2018).

The medical perspective, including therapeutic art intervention and recreational art activities, emphasises the internal values and social well-being gained through participation in art activities, and do not necessarily value a higher level of artistic skill or creative achievement (Rostron, 2010;

Richardson, 2016; Evans et al., 2017). However, professionalism in the art world requires more than being creative and gaining self-fulfilment. It requires professional artistic skills, social interaction and engagement with the public (Orchard, 2000; Vick & Sexton-Radek, 2008; Newsinger & Green, 2016). Art participants with cognitive impairment including ASD, intellectual, and cognitive disabilities strive to develop their artistic skills and social interaction as an artist, but the medical model of disability still tends to attribute pathological labels to those artists' position as outsiders (Wexler & Derby, 2015; Richard et al., 2019; Cachia, 2014). Solvang (2018) explains that "artist outsiders are defined by their difference from their audience and by their mental and social dysfunctionalities regarding prevailing standards of normal behaviours" (pp.241, 242).

The outsider's approach to art is in the "anti-conventional nature of the artmaking itself", "authenticity", "idiosyncrasy" and "unworldly distance from artistic norms", but sensational and challenging visual experiences thrill the audience (Wexler & Derby, 2015, p.131). Solvang (2018) claims that 'authenticity' is a keyword to assess the value of outsider artwork as 'being different' and eliciting 'appreciation from collectors'. He also emphasises that the primary social role of the outsiders is outside of the art world. The mainstream art establishment should value and promote the artwork of artists with disabilities "as valuable artefacts that present meaningful experiences and ideas" (p.138) rather than segregating it as outsider art (Wexler & Derby, 2015).

2.1.3 Disability arts
The disability art movement has been significantly influential in developing theoretical sources to transcend the division between the medical and the social model of disability (Swain & French, 2000 cited in Stöckl, 2014). Disability art initially aims to share the disability experience as an artistic and expressive form by artists with disabilities (Solvang, 2012, 2018; Kang, 2010; Walker et al., 2019). The powerful definition creates the connection between artists with disabilities and audience with disability in terms of sharing their identities and gaining pride (Solvang, 2012, 2018; Chandler et al., 2018; Newsinger & Green, 2016). This cultural perspective of art emphasises that "any artistic expression is thus another aspect of a complex social world" (p.37), rather than the production of an aesthetic artefact (Stöckl, 2014). The visual messages of disability art also can be an alternative communication beyond traditional speech and writing between artists with disabilities and an audience who are not living with a disability to understand disability experiences. Swain and French (cited in Stöckl, 2014) suggest the concept of the Affirmative Model of Disability beyond the debates of the medical and social models of disability. The affirmative model of disability emphasises "citizenship rights movements" and "the expression of being proud, angry and strong" amongst people with disabilities (Stöckl, 2014, p.38). Disability is valuable and significant as a subjective asset

in disability art (Sandahl, 2018; Stöckl, 2014; Solvang, 2012; Bang & Kim, 2015). Disability arts movement has created opportunities for individuals with disabilities to express the demand to be "equal but different" (Stöckl, 2014, p.39).

Disability art has developed in two main phases; the first is to define the disability rights movement through a robust definition of Disability Art; the second phase emphasises broadening the participation of artists with disabilities in mainstream art (Solvang, 2018; Bang & Kim, 2015; Newsinger & Green, 2016). Artists with disabilities demand to perform or exhibit their creative work for a mainstream audience by using a "combination of disability issues and non-disability issues" (Solvang, 2018, p.243). However, Sandahl (2018) argues that mainstream art has the assumption that "disabled people are consumers rather than producers of the arts" (p.84). Mainstream art also expects artists with disabilities to show extraordinary talents, higher than that expected of artists who do not identify as having a disability (Sandahl, 2018). Some artists with disabilities do not necessarily identify themselves as a disabled artist or use disability as content in their art (Chandler, 2018; Sandahl, 2018).

Nevertheless, artists with disabilities encounter fewer opportunities, as well as confronting inequality, to be a member of the mainstream art establishment, because being labelled as disabled is culturally devalued (Solvang, 2012; Vick & Sexton-Radek, 2008; Chandler et al., 2018; Rice et al., 2015; Ludwig, 2012; Grant, 2014). Solvang (2018) advocates that artists with disabilities also endeavour to "move disability out of the ghetto and into the mainstream, not leaving behind the spirit of anti-discrimination" (p.243). The current issue in disability art is the second phase, which concerns difficulties of being a part of the mainstream art movement to create equal opportunities to share their artistic achievement with the broader mainstream audience (Solvang, 2012, 2018; Sandahl, 2018; Chandler, 2018; Stöckl, 2014; Bang & Kim, 2015). Even though artists with disabilities strive to develop their artistic careers to enter in the mainstream art establishment, it is difficult for them to be a part of the mainstream unless the mainstream art establishment becomes more accepting of and responsive to diverse artwork, without any bias.

2.2 Public recognition as a professional artist for artists with cognitive impairment

2.2.1 Professionalism in mainstream art

The conventional definition of a 'professional artist' is closely related to the institutional theory of art definition, which emphasises that artefacts created by an artist need to be recognised by the

mainstream art world (Fokt, 2013; Cachia, 2014). The Canadian Artists' Representation le Front des Artistes Canadiens (CAR-FAC) determines a professional artist to be anyone who: "makes a living through art"; who has "educational qualifications" in any art area; who "teaches arts"; who "regularly participates in solo or group exhibitions; and who is "recognised by other professional artists as an artist" (Bain, 2005, p.32). A professional art career essentially requires "successful claim and defence of professional status through the construction and maintenance of an artistic identity" (Bain, 2005, p.34). Distinguishing a professional artist from an art hobbyist within the institutional and definitional boundaries of the qualifying art profession is significant to guarantee a degree of economic and social status for artists (Bain, 2005; Cachia, 2014; Kang, 2010; Nyqvist & Stjerna, 2017). The art profession is seen as a "sacred" profession, which creates something of "universal and permanent value" (Simpson 1981, p.5 cited in Bain 2005, p.30). However, Kelly (1974, p.138 cited in Bain 2005) argues that art is also a business that needs the approach taken to capitalist enterprises. Contemporary artists are required to be "experimental, innovative and creative" as well as developing a "distinctive and marketable individuality" to be a professional artist (Bain, 2005).

2.2.2 Creativity and artists with cognitive impairment

On the question of being an artist, creativity is accorded to be the most critical aspect. The conventional interpretation of creativity is described as an ability to "challenge", "inspire", "transform", "one of the highest-level performances", and "accomplishment to which humankind can aspire" (Taylor, 1988, p.99 cited in Bain, 2005, p.30). The public perception admires creativity as insightful, wise, divine, productive, but also as a "prized feature of the human mind" (Boden, 1994, p.1 cited in Bain, 2005, p.30). However, when it comes to artists with cognitive impairment, the public audience consciously or unconsciously tends to be sceptical about the creativity of artists with cognitive impairment, whether their artefacts are qualified enough to be seen as professional or just a challenged artwork done by a disabled person (Solvang, 2018; Sandahl, 2018; Wexler & Derby, 2015; Vick & Sexton-Radek, 2008). The conventional perception of creativity is conflicted with the culturally devalued image of disability as 'inadequate' and 'incapable' when the public audience views the artefacts created by artists with cognitive impairment (Solvang, 2018; Sandahl, 2018; O'Farrell, 2017; Rice et al., 2015; Ludwig, 2012). Artists who have cognitive impairment seem to be incapable of meeting the expectation of creativity according to the conventionality of art practice.

However, psychological research based on a substantial body of empirically grounded literature on the personality of artists finds that the characteristics of artistic persons are; "hypersensitive", "aggressive", "autonomous", "independent", "preoccupied with work to the exclusion of social activity", "intolerant of order", "seeking novelty and change", "emotionally labile" and "opposed to

the conventional" (Steptoe, 1998, p. 253 cited in Bain, 2005, p.30). The psychological perspective of artistic persons does not necessarily emphasise the superiority of creativity as a human faculty but more likely reflects instability of artists for being creative. Derby (2012) found that artists with cognitive impairment who have displayed exceptional artistic talents tend to have ASD, and they also have profound "visual acuity" and "memory". Regardless, the reality is that mainstream art has the higher expectation of credibility for artists in terms of institutional qualifications and economic productivity as well as creativity (Newsinger & Green, 2016; Cachia, 2014; Bain, 2005). In this reality, it is difficult for a marginalised artist to be acknowledged as a professional artist. This applies to such artists as those of Aboriginal background; who have disability" or come from minority cultural backgrounds.

2.3 Support for possibility

2.3.1 Mentorship

It is difficult for artists with cognitive impairment to attain a formal qualification in art through mainstream education, such as art college, university, or art studio internship, unless an appropriate course is offered with individual supports for artists with cognitive impairment. Artists with cognitive impairment still need an alternative pathway to develop their artistic skills and to pursue opportunities to connect with the mainstream art establishment. Collaborative art can cultivate mentorship between artists with cognitive impairment and professional artists from mainstream art (Walker et al., 2019; Reed et al., 2015). According to Reed et al. (2015), appropriately matched mentorship showed significant improvement in social relationships because the mentor played a support role in problem solving and reducing stress. Artists with cognitive impairment could gradually develop their artistic skills and broaden their artistic interests through shared goals of creating something together with mentor artists (Reed et al., 2015; Walker et al., 2019; Goddard, 2015). Wooster (2009 cited in Goddard, 2015) suggests that an inclusive approach to the art is to create an environment for both artists with cognitive impairment and artists living without a disability. An empowering structure should be embedded in mentorship programs for artists with cognitive impairment, but the mentor artist should be characterised as a 'co-creator', not as a 'controller', of the collaborative artwork (Goddard, 2015).

2.3.2 Social Role Valorisation (SRV) in art

Visual arts has been an area where individuals with cognitive impairment could show their artistic capabilities and creativity, and their involvement includes therapeutic intervention, leisure activity for social connection; and being more productive by pursuing artistic careers (Bendle and Patterson,

2009; Heenan, 2006; Wolfensberger, 2000 cited in Onyx et al., 2018; Katz, 1996; Vick & Sexton-Radek, 2008; Richard et al., 2019). Social Role Valorisation (SRV) introduced by Wolfensberger (1985) aims to create opportunities for devalued populations such as individuals with physical or mental disabilities to have socially valued roles by enabling, establishing, enhancing, maintaining and empowering them to participate in socially valued roles (Wolfensberger, 1985, 1998, 2000, cited Aubry et al., 2013; Kang, 2010; Vick & Sexton-Radek, 2008; Newsinger & Green, 2016; Grant, 2014; Ludwig, 2012). Creating opportunities for SRV in art practice can produce benefits, such as life satisfaction, self-esteem, and personal competencies through building mentorship programs between artists with cognitive impairment and professional artists living without disabilities (Wolfensberger & Thomas, 1981, cited Aubry et al., 2013; Ludwig, 2012; Grant, 2014). Social scientists suggested three strategies for changing the public perception of social devaluation of individuals with disabilities: "protest", "education" and "contact between individuals with disabilities and those without" (Ludwig, 2012). Empowering artists with cognitive impairment can be necessary to reflect their voice in the process of development, planning and decision-making for their art practice (Grant, 2014; Newsinger & Green, 2016). Furthermore, artists with cognitive impairment can pursue more opportunities to be involved in the mainstream art establishment through mentorship programs, such as collaborative or group exhibitions.

2.4 Critique of key studies and research

This current study reviewed eight previous studies and research (Appendix 3) on community-based art practices and social meaning of disability art. All of the reviewed studies addressed not only the importance and benefits of people with cognitive disabilities participating in art practice, but also possibilities of developing art practice for people with cognitive disabilities as Social Role Valorisation (Vick & Sexton-Radek, 2008; Ludwig, 2012; Solvang, 2012; Grant, 2014; Nyqvist & Stjerna, 2017; Chandler et al., 2018; Richards et al., 2019; Walker et al., 2019). According to Vick and Sexton-Radek (2008), the new trend of viewing people with cognitive impairment participating in their art practice is to see art as a career rather than as therapeutic art. All eight studies reviewed for this current study discussed the need to cultivate disability art and art practices of people with cognitive impairment who require communication alternatives to express themselves to create socially valued roles for them (Vick & Sexton-Radek, 2008; Ludwig, 2012; Solvang, 2012; Grant, 2014; Nyqvist & Stjerna, 2017; Chandler et al., 2018; Richards et al., 2019; Walker et al., 2019). The studies also pointed out barriers for people with cognitive impairment to develop their art practice, such as a lack of mentorship opportunities and the public misconception of cognitive impairment (Ludwig, 2012; Grant, 2014).

However, none of the studies made practical or functional suggestions to build a pathway for the development of art practices as an employment opportunity. It found the gap between the theoretical findings and needs of practical strategies to be implemented in reality. For the development of art careers as employment opportunities, practical questions should be addressed:

- How to develop artistic skills and to broaden artistic interests.
- How to promote artwork of artists with cognitive impairment in the public marketplace.
- How to make an artist agreement regarding intellectual property, copyright and licensing if the artists with cognitive impairment work with collaborators, mentors or commercial companies.
- How to manage the complexity of the government disability pension and extra income, if any.
- How to share the profits of sale of artwork between art organisations and artists with cognitive impairment.
- How to involve artists with cognitive impairment in collaborative projects or commissioned works if the artists have communication challenges.

Those practical and functional questions are critical to build effective strategies or frameworks to facilitate the development of art careers for artists with cognitive impairment. Without knowing how commercial industries and contemporary art business work (Bain, 2005), developing art practices as employment opportunities would not be feasible. This current study focused on exploring the feasibility and practical strategies the art staff participants applied in the art practice of the artists with cognitive impairment by asking the questions above. This research investigated more details of challenges and enablers to pursue art careers as a professional artist for artists with cognitive impairment.

2.5 Research questions

The following questions will be addressed in this current research study:
- What are the challenges as an artist living with cognitive impairment?
- What are the enablers to make artistic progress towards public recognition as a professional artist?

2.6 Summary

This chapter has reviewed the studies on art's roles and its significance in disability in general, but it also has explored potential challenges and enablers for artists with cognitive impairment. The review

started with a question of seeking art definitions from different perspectives and interpretations, and it explored the meanings and functions of art in disability and individuals with cognitive impairment in general. The review mainly focused on investigating any difficulties that artists with cognitive impairment have faced when they seek public recognition as a professional artist in the mainstream art establishment. This chapter concluded with a discussion urging an alternative pathway to support the development of artistic careers for artists with cognitive impairment and their active involvement in the mainstream art establishment.

Chapter 3
Methods

3.1 Study design

This current qualitative research project aimed to explore and to discuss what challenges and enablers the individual artists with cognitive impairment experienced through developing their art practice as a professional artist. The nature of individual characteristics of artists with cognitive impairment including ASD, intellectual or cognitive disabilities in terms of mental health and behaviours is complex and diverse (Ganz et al., 2012; Qi et al., 2018; Durrani & Shahar, 2014). Accordingly, research on people with cognitive impairment used alternative ways of conducting inclusive research, such as an art-based research workshop, creative and visual methods and an asset-based approach (Richards et al., 2019; Chandler et al.,0 2018; Walker et al., 2019). Art-based research workshop approaches require a long period to collect rigorous data to understand the depth of the lives and individual stories of research subjects. For example, Richards et al. (2019) conducted 45 workshops over 12 months and reviewed 40 participants' artworks for inclusion and participation in community-based research. The other widely used research approach was to conduct data collection through an electronic survey with art practitioners or art administrators who are related to artists with cognitive impairment (Grant, 2014; Ludwig, 2012).

Inclusive research has people with learning disabilities in an active role as instigator, interviewer, data analyst or author, more than just subjects of research (Walmsley & Johnson, 2003). Designing an inclusive research process requires a longer process to build a relationship and trust between a researcher and participants with cognitive impairment prior to having an in-depth conversation (Brown and Brown, 2013; Ellis, 2017). This is to avoid research unintentionally creating circumstances that could disempower participants with cognitive impairment. For example, Ellis (2017) recognised that in the inclusive research process Ellis (2017) conducted, the action of the researcher could be seen as denying the voice of the co-researchers with learning disabilities. Ellis (2017) explained that "This was not done to exert my social power over the co-researchers, thus deliberately disempowering them, but in order to maintain the opportunity as whole and to ensure the project remained viable". To avoid such circumstances, the researcher must be insightful and establish trust and a relationship with potential participants with cognitive impairment. However, this current research had significant limitations to build an in-depth inclusive research process:

- there existed a short-period of time to conduct research to build a relationship with potential participants for rich and rigorous data collection and analysis;

- a lack of funding (only relied on personal funding);

- limited geographical location if inclusive research is conducted; and

- potential participants had communication challenges to articulate their ideas, such as explaining their rights as an artist and financial management.

Regarding the limitations, this current research needed a methodology to build a depth of knowledge on the subjects' experiences; backgrounds, including environmental settings; and personalities to analyse and interpret without the need for direct verbal communication (Petry et al., 2005; Nind, 2008). It also focused on strategies for developing art careers for the artists with cognitive impairment in term of business, legal protection, policy, complexity of funding management and marketing the artwork, which questions might be challenging for the artists to explain in detail. A direct approach to artists with cognitive impairment was also considered to be likely to raise the risk of anxiety or disrupt research processes by using inappropriate language and behaviours, without a depth of understanding for the individual differences of the artists (Brown and Brown, 2013). The communication and social interaction difficulties had to be taken into consideration for some artists with cognitive impairment when designing research methods in this current study.

Therefore, the research methods employed 'proxy' intervention (Brown and Brown, 2013, p. 133), which is the concept of getting information or explanation about the life of artists with cognitive impairment through perspectives of significant others closely related to them, such as parents, primary carers or other family members (Petry et al., 2005). A qualitative methodology has strength in understanding "subjective meaning of the phenomena" through observation, analysis and interpretation of personal experiences and their social positions (Saks & Allsop, 2013, p. 27). A case study approach was implemented to provide an in-depth understanding of the individual cases of artists with cognitive impairment in their natural setting in order to elucidate complexities and contexts of their experiences (Punch, 2009; Petry et al., 2005). According to Petry et al. (2005) and Wood et al. (2014), their research employed a qualitative case study methodology by applying a phenomenological research method and an interpretative paradigm to explore the lives of individuals with profound cognitive impairment including autism, mental, and intellectual disabilities.

In this present study, data collection involved semi-structured interviews, emails and fieldnotes undertaken and obtained with the artistic supporters and caregivers of two artists with cognitive impairment. These significant others, who were actively involved in supporting the artists, acted as a proxy who could speak on their behalf with the agreement of the artists themselves (Petry et al.,

2005). Consent forms were sent to the potential participants who were the caregivers of the two artists with cognitive impairment before the interview, and the caregivers had a discussion with the artists, in their preferred mode of communication, in relation to participation in the research. The research targeted two groups; the first group was 'caregivers' including parents, primary carers, or other family members spending most time caring for the artists with cognitive impairment; the second group was 'artistic supporters' including art community members, art staff, mentors, art teachers or anyone who had artistically supported the artists with cognitive impairment for more than three years. The reason for interviewing two different groups was to build the depth of observation about the experiences of artists with cognitive impairment through the perspectives of the insiders and outsiders so as to achieve the level of understanding necessary to build case studies that answer the research questions. An analytical approach to social life must consider the connection between the 'insider' perspective and the 'outsider' perspective (Green & Thorogood, 2014, p.155). As an insider, the caregivers had an established bond with the artists and had a deep understanding of the artists based on daily life and social realities (Dwyer & Buckle, 2009 cited in Amanda, 2012). Hence, the caregivers' insider perspective could provide detailed information and interpretation of what challenges and enablers the artists had experienced throughout the development of their art practice. The art staff participants could represent the perspective of an outsider on the same questions, which could be more objective and correct in interpreting the questions (Banks, 1998; O'Conner, 2004 cited in Amanda, 2012).

3.2 Participant selection and recruitment

This present qualitative research considered gender balance and cultural diversity, even though the target number of participants was small. The research focused on the artists with cognitive impairment who have been participating in creative projects or art activities more than three years with the intention of gaining public recognition as a professional artist in the mainstream art establishment. The population of potential participants who could meet these conditions was relatively small. Consequently, the researcher needed support from the art organisations to search for eligible potential participants who were willing to participate in the project. As the research participation process may be relatively complicated for some caregivers to understand, the organisations were able to assist potential participants in understanding the process. Some potential participants felt more comfortable talking with staff at the art organisations rather than contacting the researcher directly. Given this, it was more appropriate to use a direct recruitment approach. Senior staff (e.g. art coordinator or director) were tasked with recruiting potential participants

because they had the most knowledge of the individual artists with cognitive impairment including their art activities, intent, artistic potential, and individual needs and strengths.

The sample size for the current study initially targeted three artists (including male and female) with cognitive impairment. Implementing the 'proxy' intervention method, the actual interviewees from whom to collect data about the artists' experience included significant others such as caregivers and artistic supporters. The intention was to interview one of each group at least: one parent or carer; and one main art supporter, as proxies in each case, to describe the personal and artistic experiences of an artist with cognitive impairment, in terms of making their artistic progress and developing their career. Participation of three artists with cognitive impairment in the case studies would be completely voluntary. The sample size of this qualitative study was narrow and purposive, based on qualitative phenomenological approaches with the intention to facilitate observations and comparisons (Saks & Allsop, 2013; Fisher & Stenner, 2011; Wood et al., 2014).

Sampling focused on a group or particular community for artists with cognitive impairment who met the specific conditions. Seven art organisations in Australia and South Korea were purposively selected: two art organisations in South Australia; art organisation B in Sydney; art organisation A, and another art organisation in Melbourne; and art organisations C and D in South Korea. The sampling technique involved eight steps in a purposive recruitment approach:

Step 1 The principal researcher sent emails to the targeted art organisations with the letter of introduction for the research project (Appendix 4) and the project brochure in PDF (Appendix 11).

Step 2 The principal researcher followed up the emails by emailing the organisations to confirm receipt of the emails and to ascertain their level of interest in participating in the research project.

Step 3 The principal researcher sent further information via email including the information sheets, consent forms and interview questions (see Appendices 5, 6, 7, 8 and 9 respectively) when the organisations required. The organisations discussed the project with potential participants including caregivers of artists with cognitive impairment and their artistic supporters.

Step 4 If required, hardcopies of the project brochure and the related documents, were posted out by the researcher for potential participants who were interested in the research project.

Step 5 Before making the decision to participate in the interview by a proxy intervention on the artist's behalf, the caregiver and the art staff talked with the artist to establish their willingness to be involved in the research. The artist needed to sign the consent form if they could, otherwise, the

caregiver signed the consent as a co-participant. As the caregivers and the art staff of the artists had already earned the trust and formed a relationship with the artists, they were able to explain the research project and how the artists could participate in the research indirectly.

Step 6 Once the artists with cognitive impairment and their caregivers agreed to participate in the research, they contacted the art staff of the art organisation where they were involved.

Step 7 If more than three artists agreed to participate, the principal researcher would select the three artists who had been involved in art for the longest period and who had the most experience in exhibitions and/or commercialising their artwork. The artist information was found with the permission of the artists and their caregivers.

Step 8 If the participants had any concerns or questions, they could email the principal researcher directly or through the art staff who initially contacted the participants.

The information brochure (Appendix 11) and the information sheets (Appendix 5, Appendix 6) included the project aims, social contribution, benefits of research participation and contact details of the researchers. The consent forms (Appendix 7, Appendix 8) and the semi-structured interview questions (Appendix 9) were provided to the caregivers of the artists, as required, to assist with their decision-making regarding possible participation.

3.3 Ethical considerations

This present study aimed to meet ethical standards throughout the entire research process of working with participants who were involved directly and indirectly. The researcher undertook respectful approaches and brought a deeper understanding of research values and motives for participants before participation and during data collection, analysis, and report writing (Saks & Allsop, 2013; Nind, 2008; Petry et al., 2005; Wood et al., 2014). The following steps were taken to an ethical approach.

Ethics approval was granted for the involvement of vulnerable populations who have a form of severe disability (Project No.: 8168, see Appendix 10).

All participants were informed about the research including the topic, aims, public benefits, consents, confidentiality, and the process of the participation based on healthcare ethics: "autonomy"; "beneficence"; "non-maleficence"; and "justice" (Beauchamp & Childress, 1983 cited in Green & Thorogood, 2014, p.66).

Due to the complex communication needs and behavioural differences of the individual artists with cognitive impairment, the artists indirectly participated in the project through their caregivers and artistic supporters (Brown & Brown, 2003; Petry et al., 2005).

Interview questions were handed out to the caregivers to collect the information from the artists before interviews, so the caregivers were able to get responses from the artists about themselves by using appropriate language for the artist's level of understanding in a comfortable environment instead of the principal researcher directly talking to the artists.

The different levels of communication skills of the Individual artists with cognitive impairment were taken into consideration. Unless the interviewer had a good understanding of the individual artists' language levels and styles, it would not be possible for the interviewer to illicit the sought after information from them directly. Therefore, the interviewees (caregivers) were selected to act as proxy to convey responses of the artists to the researcher on the artists' behalf.

Each interview was conducted, with the consent of both the caregivers and the artists, by using audio recording and transcripts for analysis. Transcripts were approved by the interviewees before analysis.

Participation in the research was completely voluntary, and participants were informed that they could stop or withdraw anytime they wanted to.

The researcher provided information on counselling options for participants regarding any emotional or psychological support during the interview or afterwards. The counselling information for participants in Australia was provided: Lifeline (see Appendix 11). Seoul Psychological Support information was provided to Korean participants (see Appendix 11).

The current study was conducted with ethical approval from the Flinders University Social Behavioural Research Ethics Committee (SBREC) (Project No.: 8168, see Appendix 10).

3.4 Data collection

3.4.1 Semi-structured Interviews

Data were collected through semi-structured interviews which were designed for proxy intervention on behalf of artists with cognitive impairment by involving significant others who related to the artists (Brown & Brown, 2013; Petry et al., 2005; Amanda, 2012). The initial project aim, to interview three artists with cognitive impairment, was not achieved because the caregivers and artists with

cognitive impairment involved in art organisations C and D, did not want to participate in the interview. However, art staff at organisations C and D willingly participated in an interview to share their experience of working with artists with cognitive impairment in general, without specifying the names or identities of the artists. Therefore, finally two specific artists with cognitive impairment indirectly participated in the semi-structured interview through their caregivers and the art staff of the studios where they were involved. Interviews were conducted for approximately 60 minutes, and the interviewees were given the information about the process of the interview, including the potential questions, consents, audio recording and confidentiality agreements prior to the interview.

The interview questions were built around two concepts; 'challenges' and 'enablers' in terms of developing the art career of artists with cognitive impairment. Questions also focused on the phenomena across the individual cases of artists with cognitive impairment. Data collection focused on providing unitary information to study by interrelating various factors of individual cases of two artists with cognitive impairment (Theordorson and Theordorson, 1969 cited in Punch 2009; Green & Thorogood, 2014). This mode of data collection was expected to provide "a snapshot of the behaviour or perspectives of a hard-to-reach or stigmatised group inaccessible via other methods" (Lambert et al., 1995 cited in Saks & Allsop, 2013, p.109).

Challenges (e.g. personal environmental setting; financial situation; physical and mental assistance needs to access art activities; emotional, cognitive, and behavioural challenges; social challenges; societal barriers, etc.)

Enablers (e.g. personal aspiration; positive personality; commitment; exceptional artistic talents; family supports; community support; mentorship program; opportunity for social connection; support to sell artwork, etc.)

3.5 Data analysis

The collected data from the interview with Korean participants were transcribed and translated, and all the interview transcripts with both Korean and Australian participants were analysed by using a thematic and interpretative phenomenological approach. This present research implemented a thematic analysis approach as a foundational method for qualitative research (Braun & Clarke, 2006; Tonon & Alvarado, 2012). Thematic analysis refers to a method following the sequence of identifying, analysing and reporting patterns based on major themes, which also were categorised under subthemes within data, and which also provide a flexibility and efficiency for a rich and detailed result (Braun & Clarke, 2006; Tonon & Alvarado, 2012). This particular research area on artists with

cognitive impairment and their art career development has relatively few research studies or specific theoretical analysis or frameworks. This current study applied a constant comparative and iterative approach to analyse the data collection and to build a proposition by identifying challenges and enablers of the individual artists (Taylor et al., 2016).

Data analysis was undertaken using an interpretative phenomenological approach, referred to as 'hermeneutics', to describe, understand and interpret the experiences of the individual artists with cognitive impairment (Touhy et al., 2013). The qualitative data analysis was difficult because it was not a mechanical or technical process but "a process of inductive reasoning, thinking and theorising" (Taylor et al., 2016, p.159). Data analysis focused on two aspects: 'challenges' and 'enablers' by taking the two different perspectives of insiders and outsiders on artists with cognitive impairment. There are four concepts in interpretative phenomenology (Touhy et al., 2013):

- 'being-in-the world';
- 'fore-structures';
- 'life-world existential themes'; and
- 'hermeneutic circle'.

This present qualitative research aimed to understand and reflect on how the artists with cognitive impairment experienced the process of developing their art practice in real life, which is suitable to investigate the concept of 'life-world existential themes' (van Manen, 1990 cited in Touhy et al., 2013). The approach of life-world existential themes as an interpretative phenomenology has four aspects which include 'lived space', 'lived time', 'lived body' and 'lived human relation' (van Manen & Adam, 2010; Touhy et al., 2013). The researcher explored the relationship between the artistic supporters and the artists and 'life history' of the artists through proxy intervention interviews with their caregivers and artistic supporters (Green & Thorogood, 2014; Touhy et al., 2013). This current research aimed to understand and interpret the experiences of the artists with cognitive impairment to determine the meaning of their experiences which would possibly influence present and future experiences (Touhy et al., 2013; Berndtsson et al., 2007). The result of the data analysis in this current study has potential to develop a proposition which can be assessed for 'applicability' and 'transferability' to other situations in future research (Punch, 2009).

3.6 Rigour in qualitative research

This current qualitative research study considers that "the process of questioning is an integral part of understanding the unfolding lives and perspectives of others" (Agee, 2009, p.432). Despite many criticisms about a case study as an insufficient rigorous or generalisable research method, Yin (2009

cited in Cronin, 2014) argues that a case study is still a powerful method to explain real-life, causal links and the subjective richness of individual experiences in a particular context. The case study research in this current study adopted four approaches for determining the rigour of the qualitative research (Houghton et al., 2013; Thomas & Magilvy, 2011; Yin, 2014):

- credibility;
- dependability;
- confirmability; and
- transferability.

Credibility considers the value and believability of findings through case studies as qualitative research, and requires the researcher to spend sufficient time in the case studies to attain a depth of understanding of the phenomena (Altheide & Johnson, 1994 cited in Houghton et al., 2013). In this current research study, the researcher ensured that both participants, including the caregivers and art staff, honestly projected the life experiences of the two artists with cognitive impairment, on their behalf without any presumption. There was no pressure for the participants to answer if they had no ideas or declined to respond to the semi-structured interview questions. The primary researcher visited all the sites of the phenomena being investigated to interview the interview participants in person to understand the environmental settings (Houghton et al., 2013; Yin, 2014). The completeness of data collection was achieved by gathering multiple perspectives of the insiders and outsiders who had been involved in the development of art practices for the two artists with cognitive impairments (Shih, 1998; Casey & Murphy, 2009 cited in Houghton et al., 2013).

Dependability refers to reliability in quantitative terms, and which has been achieved by outlining the decisions made throughout the research process (Thomas & Magilvy, 2011; Houghton et al., 2013). An audit trail was achieved by the following steps: describing the purpose of this case study research; explaining how and why the specific participants—the two artists with cognitive impairments—were selected for the case study; describing the process of the data collection through using an intervening 'proxy' approach; and discussing the interpretations of the research findings (Thomas & Magilvy, 2011; Houghton et al., 2013; Brown & Brown, 2003). Two research supervisors were consulted throughout the research process, including the data analysis process, to establish a context of dependability (Thomas & Magilvy, 2011). The data collection and analysis were examined and reviewed by the principal researcher and two research supervisors on multiple occasions.

Transferability considers "how one determines the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects or participants", which is an equivalent term to 'external validity' in quantitative research (Lincoln & Guba, 1985, p.290 cited in Thomas & Magilvy, 2011, p.153). This present case study research established transferability by providing a detailed description of the demographics and geographic boundaries (Thomas & Magilvy, 2011). The research findings from the semi-structured interview presented appropriate quotations from the participants as raw data without any editing or conceptual interpretation under the themes. The presentation of the findings can provide an opportunity for readers to decide whether the findings are transferable to another context or not (Graneheim & Lundman, 2004 cited in Houghton et al., 2013).

Confirmability occurs when credibility, transferability and dependability have been established, which term is similar to objectivity in quantitative research (Thomas & Magilvy, 2011; Houghton et al., 2013). The qualitative research must be "reflective of maintaining a sense of awareness and openness to the study" (Thomas & Magilvy, 2011, p.154). This present case study adopted a reflective diary; audio recording for interviews; and maintaining all the records of written and verbal communications with the participants throughout the research process in order to highlight the transparency of the process (Houghton et al., 2013; Thomas & Magilvy, 2011; Jootun et al., 2009). After transcribing the audio records of the interviews with the participants, the transcripts were sent to the participants to confirm if they required any correction or addition. Reflexibility is critical to develop confirmability of the qualitative research, which builds a sense of trust in credibility and applicability of the findings (Thomas & Magilvy, 2011).

3.7 Summary

This chapter provides research methodological information about a phenomenological case study as qualitative research, including research design, data collection, data analysis, ethical concerns, and research rigour. The results of the research are outlined in Chapter 4.

Chapter 4
Results

4.1 Introduction

This chapter details the outcomes of the interviews with two caregivers of two artists with cognitive impairment and eight art staff members from four different art organisations for artists with cognitive impairment. The results describe their individual experiences of being a supporter and as an advocate for the artists. The identities of the interviewees, including their names and the names of the organisations, are changed to protect the confidentiality of the participants. The results of transcript analysis are presented under the two thematic research questions: 1) challenges and 2) enablers. Results revealed a large range of enablers compared to the other question. It can be seen as a positive outcome of the research. The direct quotes of participants are presented using their pseudonyms and are presented in italics with quotation marks or in indented paragraphs.

4.2 Participant information

This current study initially aimed to reflect individual experiences of three artists with cognitive impairment through the perspectives of insiders (caregivers) and outsiders (art staff members). The invitations for the purposive recruitment were initially sent out to seven art organisations across Australia and South Korea to search for three artists with cognitive impairment interested in participating in this study. Unfortunately, only two caregivers responded on behalf of the artists with cognitive impairment. However, four art organisations showed their willingness to participate in the interview. Therefore, this study included 10 participants in total: two caregivers of two artists with cognitive impairment who actively develop their art practice at two different art organisations in Sydney and Melbourne (Table 1); and eight art staff members including two art staff members at an art organisation in Melbourne; two art staff from an art organisation in Sydney; three art staff from an art organisation and one CEO of a design company in Seoul in South Korea (Table 2). Six participant caregivers and art staff were directly involved with the two artists (Table 2). Four art staff members from Korean art organisations shared culturally and socially diverse perspectives on their experience of working with artists with cognitive impairment in South Korea (Appendix 1). Even though the number of participants was limited, the data collected through the interviews were rich and insightful as an outcome of a qualitative study.

Table 1 Artist demographics

Pseudonym	Sex	Age	Art organisation	Main areas of art practice	Years of practice
David	Male	44	Melbourne	Painting, crafts and sculpture	20 years
Sam	Male	45	Sydney	Weaving, painting	6 years

Table 2 Participant demographics

Pseudonym	Sex	Art organisation	Relationship to the artist	Position/role
Sarah	F	Art organisation A in Melbourne	Half-sister of David	N/A
Michael	M	Art organisation B in Sydney	Father of Sam	N/A
Jane	F	Art organisation A in Melbourne	Artistic supporter for David	Art director
Tom	M	Art organisation A in Melbourne	Artistic supporter for David	Studio manager
Helen	F	Art organisation B in Sydney	Artistic supporter for Sam	CEO
Emily	F	Art organisation B in Sydney	Artistic supporter for Sam	Studio manager
Kim	F	Design company C in Seoul, South Korea	N/A	CEO
Sun	F	Art organisation D in Seoul, South Korea	N/A	Studio manager
Park	M	Art organisation D in Seoul, South Korea	N/A	Art director
Lee	F	Art organisation D in Seoul, South Korea	N/A	Graphic designer

4.3 Research Question 1

What are the challenges as an artist living with cognitive impairment?

Thematic analysis of the interview transcripts revealed that artists with cognitive impairment and their caregivers have experienced significant challenges represented under four themes: 1) individual challenges; 2) systemic challenges; 3) societal challenges; 4) pursuit of professionalism. (See Figure 4.1)

4.3.1 Theme 1 – Individual challenges

4.3.1.1 Subtheme 1.1 – Physical health and mental challenges

The caregivers and all art staff members described individually different challenges around physical and mental conditions for the artists, Sam and David as well as other artists with cognitive impairment. These challenges were in the main around physical stamina, emotional regulation and focus on the task at hand. For example, Sarah as a caregiver for David commented that *"It had been reported that he had an intellectual disability and he would not be able to work in conventional employment… he is displaying many behaviours that are on autism spectrum. I think David's greatest disadvantage with that is actually his own momentum, his own self, finds it hard to focus in one direction and he can slip away quite easily… he does suffer from quite number of health issues as well,*

physical health issues.... Those sorts of things are challenging. So, he can… he loses his energy quite fast. That's challenging in his art practice always."

Figure 4.1   Overview of challenges for developing artistic careers of the artists

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Individual Challenges	Systemic Challenges	Societal Challenges	Pursuit of Professionalisam
Physical health & mental challenges	Searching for funding	Public perception of artists with cognitive impairment	Difficulty understanding the artists' intent for their art practice
Communication & behavioural challenges	Financial management for the individual artists	Attiutudes of mainstream art communities	Diverse interpretations of professionalism in art
A lack of confidence on the part of both artists and their caregivers	Managing the interrelationship between government funding and extra income		
	Meeting the demands of clients and new applicants		
	Lack of space to create an appropriate environment for artists with sensory issues		
	Multiple duties for limited number of art staff members		

4.3.1.2 Subtheme 1.2 – Communication and behavioural challenges

All participants, both staff and caregivers, commented on how they had to deal with challenges in communication and behavioural management when engaging with artists living with cognitive impairment. For example, Jane, a staff member from art organisation A in Australia, commented

that "*we have some people who are high functioning and people who don't speak and people who don't hear, people who have a high level of autism. We don't just have one line of communication*". In addition, Lee stated "*I also realised that emotions and behaviours of the artists could be varied and influenced depending on circumstances and environmental changes, such as weather, personal situations, seasons, what they wear for the day, and their moods. Those diverse factors influence their emotions and attitudes*". Michael, as a family member, added that "*[Sam] cannot express himself well verbally to describe what things are and what he needs. It takes a while for him to get to know people and to do things*".

4.3.1.3 Subtheme 1.3 – A lack of confidence on the part of both artists and their caregivers

All four Korean participants from art organisations C and D commented on a lack of confidence in the presented capacity of the individual artists with cognitive impairment to be successful. This lack of confidence was on the part of both artists and their caregivers when they first met art staff to discuss their artwork.

Sometimes, some parents or caregivers have a lack of understanding about the disabilities of their children, and they are highly anxious. "*They often say, 'my child can't do anything due to his/her disabilities…' or 'how could it be possible for her/him to work? I can't believe it'*" (Kim).

> *I saw that the artists [were] also concerned [about] their disabilities and what to do at the beginning. But, eventually, they found what they could be capable of through creative activities over time. And they became more confident about themselves when they saw their successful outcomes exhibited in public…. I also found that the artists felt more confidence and pride when they were drawing portraits for other people.* (Park)

Park also explained that parents or caregivers of the artists were sometimes judgemental and often not confident to show their children's artwork in public:

> *Many of the parents or caregivers were quite sceptical and judgmental towards the quality of the artwork that their children created. They often questioned us whether their drawings [were] good enough to be an artwork or not. So, sometimes, they felt ashamed to show the drawings that their children did, to us or display in public.*

4.3.2 Theme 2 – Systemic challenges

4.3.2.1 – Subtheme 2.1-Searching for funding

When discussing funding as a challenge there were differences in the experiences of Australian and Korean participants. Australian participants mentioned the National Disability Insurance Scheme

(NDIS) and other additional funding sources they could apply for, whereas, Korean participants described considerable difficulties in obtaining any level of government funding. Korean organisations are completely reliant on philanthropic sponsors and donors. Park reported that *"it is difficult to manage a non-profit community organisation in the Korean social setting. Currently, many communities are set up and managed by parents of people [who] have disabilities, but those communities have financial difficulties because they don't have enough financial support from the government or society. Without the commitment of the staff or parents in the communities, it is almost impossible to sustain those non-profit organisations".* This is in contrast to Helen who commented that income often came from government, but they also needed to find non-government funding:

Our income we get funding from government and funding from [Government organisation] as a visual art company and that we're always exploring other avenues from government to get incomes for instance. And looking at what other kinds else we are relevant, maybe multiculturalism or education.

Jane stated that the NDIS is not consistently supporting engagement in the arts as valued employment and would like to see this reconsidered*:*

I would like to see the NDIS broaden its view of economic participation of employment because at the moment they don't see what we do is building capability in terms of people's employment and economic participation.

4.3.2.2 Subtheme 2.2 – Financial management for the individual artists

All participants, staff and caregivers, regardless of cultural background agreed that the artists have challenges in managing their own finances, so they relied heavily on family members, caregivers, staff or a trustee for assistance with financial management. This was identified as being more complex under the NDIS and therefore a potential concern for the future for some caregivers. For example, Michael, Sam's caregiver commented that *"I manage Sam's NDIS finances and support him with other necessary payments and purchases. So, I self-manage Sam's NDIS but as I get older, I would like to outsource that but… our NDIS provision is a horrible challenge with procedure and priority".* Jane from Australian art organisation A commented that *"most of them don't manage their own money, some don't really understand it, but their family do… The trustee is who is responsible for this… it's very interesting".*

4.3.2.3 Subtheme 2.3 – Managing the interrelationship between government funding and extra income

Staff participants from both participating Australian art organisations explained that one of their roles is to mediate and resolve any issues around the interrelationship between the government income support the artists may receive and extra income they could earn through selling their artwork. This is not an issue in Korea as income support via a disability pension is extremely small, but the artists are not close to reaching a threshold. As revealed by Jane in the Australian context, *"it's also complicated by… their pension. If they earn a certain amount they will lose their pension. Our top artist, he doesn't get his pension anymore because he's earning between $5,000-$25,000 a month on his artwork, and which is great. But his mother has to jump through hoops because it's the art world [and] next month he might not sell anything. The income [will] never be consistent".*

4.3.2.4 Subtheme 2.4 – Meeting the demands of clients and new applicants

All of the art staff participants in both Australian and Korean art organisations reported that it was challenging to manage expectations and demands with limited funding and resources. Staff described that they had increasing demands from potential new artists and their caregivers, but they could not always meet these demands due to limited resources, including space, budget and staff. There were also demands from existing participants who want to have more time with the organisation but again, due to funding, this was not always possible. Jane, an art director from Australian art organisation A stated that *"We can't take any more here – we have 140 artists we are full. Can't have any more".* In addition, Tom, a studio manager, reported that *"We can still keep and get fresh new talented artists, but it's really hard for us because our artists generally don't leave. We get the right artists, and they enjoy what they do greatly. And if there is anything, they want to come more often than not".*

4.3.2.5 Subtheme 2.5 – Lack of space to create an appropriate environment for artists with sensory issues

Tom at art organisation A addressed the environmental challenges for some artists who have sensory issues and other artists because of the limited space. Tom said that it was challenging to create an appropriate environment and space to support such a diverse range of people with cognitive support needs. He also commented that the new business model of the NDIS added pressure for organisations to take more participants and more diverse participants in order to be sustainable and this, in turn, added additional pressure on the ability to meet individual sensory and other needs. For example, Tom stated that *"we are particularly set up for those sensory overload characteristics of a lot of the autistic artists, noise, quiet spaces, bright lights and general chaos. We*

have all that in the studio…. So, we are doing our best, but we had a space even for the artists to go in [when they] feel overload. That's the quiet challenge. Also, we've never been busier because of the NDIS, new insurance scheme. We've got a growing waiting list, but [we've] got a full capacity".

4.3.2.6 Subtheme 2.6 – Multiple duties for limited number of art staff members

The studio managers from small scale Australian art organisation B and Korean art organisation D found it challenging that they had to take on multiple roles with a limited amount of time. These multiple roles and tasks included providing personal care support for participants, undertaking administration and case management duties, liaising with families, other professionals, and government bodies and then trying to facilitate art engagement and capacity building. Poor resourcing for staff was the main reason staff needed to take on so many roles. This challenge was reported by both Australian and Korean staff. Emily, a studio manager for Australian art organisation B where Sam was a participant reported that *"I am on the floor each day with the artists and lead arts facilitator and managing the studio/volunteers/staff/guest artists and the artists themselves. I am usually the one who is across all the different projects, individual projects, group projects, deadlines and competitions…. We have time challenges and we never have enough time for everything…. We also have other administration work, emails, planning, supply orders and other types of communication for the projects and partnerships the artists are involved with…. We are liaising with [the artists'] families, dealing with other clients. Like... it… it's a big job".*

This complex juggling and multi-tasking was also reported by Park from Korean art organisation D:

> *Acting [in] an agency role is not only about making a connection between the artists and the commercial companies, but we also need to mediate all other matters, such as production process, editing the images and so forth.*

4.3.3 Theme 3 – Societal challenges

4.3.3.1 Subtheme 3.1 - Public perception of artists with cognitive impairment

Regarding the public perception of artists with cognitive impairment and their artwork in general, the staff from the arts organisations took this issue very seriously and saw the individual's engagement with art as a means of highlighting strengths and social value. There were similar public perceptions reported by Australian and Korean art organisations and caregivers. For example, Sarah, as David's caregiver, commented that people most often see David as an artist with a disability: *"Often people see them as an artist with a disability, just depends…".*

Park also commented on some of the more disappointing public perceptions around asking if the artwork of artists with cognitive impairment was accomplished with external help from others. There seems to be a lack of expectation that individuals with cognitive impairment could express such talent without significant intervention from non-disabled artists. Park stated that *"questions and doubts make the artists and their parent or caregivers very disappointed and disgraced."*

4.3.3.2 Subtheme 3.2 – Attitudes of mainstream art communities

Kim and Helen advised that the mainstream galleries did not show any interest in artwork of artists with cognitive impairment because they were under the impression that individuals with intellectual disability have no capacity and therefore they were unwilling to even consider the idea.

> *I wanted to introduce one artist with cognitive impairment because his artwork is excellent and as good as other contemporary artists out there. So, I started a conversation about the artists with disabilities with [the curator], but she had no interest at all and said they were not mainstream artists. So…. I couldn't continue the conversation.* (Kim)

> *What I have found genuinely there is misassumption [that people with] intellectual disability can't make good art. There is an assumption that I am an art therapist, but I am not an art therapist…* (Helen)

4.3.4 Theme 4: Pursuit of professionalism

4.3.4.1 Subtheme 4.1 – Difficulty understanding the artists' intent for their art practice

The art staff in both Australia and Korea reported that it was challenging to find out the artists' intent with their art practice and their goals due to communication difficulties with the artists. There was often a lack of clarity as to whether this was leisure or a desire to pursue professional status. For example, Sun, a studio manager from Korean organisation D reported that "*I am not sure whether they all want to be a professional artist or not. One thing for sure is that I can see them enjoying their time for being here and working on their artwork. But… I can't explain whether they have any goals to be a professional artist to get more public attention or love for their work*". This was supported by Tom, a studio manager from an Australian organisation. *"We have the artists who in fact the top two artists wouldn't be able to communicate what they are; as far as I know they are profoundly autistic, and they are nonverbal…. There is no way we can particularly know whether they don't want us to".*

4.3.4.2 Subtheme 4.2 – Diverse interpretations of professionalism in art

All the art staff commented that not all the artists necessarily care if they are recognised as a professional artist or not. The art staff do not encourage the artists to be recognised as a

professional in the mainstream art establishment unless it is their personal wish to do so. For example, Park from a Korean arts organisation D explained that,

We don't aim to encourage our artists to be a professional artist in mainstream art through what we do here. But if there is an artist [with cognitive impairment] who wants to be a part of the mainstream art, so the artist is developing his skills and working hard to get in there… However, most of our artists are not really looking for those opportunities, but which doesn't mean they are doing recreational art.

4.4 Research question 2

What are the enablers to make artistic progress towards public recognition as a professional artist?

Thematic analysis of the interview transcripts revealed results identifying a larger range of enablers than challenges. These enablers (Figure 4.2) were reported to support artists with cognitive impairment to develop their art practice, which includes four main themes: 1) individual enablers; 2) systemic enablers; 3) societal enablers; and 4) professionalism through SRV (Social Role Valorisation).

4.4.1 Theme 1 – Individual enablers

4.4.1.1 Subtheme 1.1 – Unique styles of the artists' work

All art staff participants from both countries commented on the quality of artwork created by the artists and their individual unique styles from the artistic perspective.

> *We don't see the unique behaviours of the artists as a trait of autism or related to disability that might be seen as a part of disability in general though. Instead, we interpret them as individual unique features for being an artist.* (Park)

> *I was really amazed by the high quality of some of the artwork that had been made there.* (Helen)

4.4.1.2 Subtheme 1.2 – Individual motivation and passion for art

Both staff and caregivers reported that from their experience artists with cognitive impairment they knew were highly motivated and enthusiastic about engagement in art activities. For example, Sarah and Michael described the individual motivation and passion of David and Sam for their art practices.

> *He always has his ability. But now he is very definite about what he wants to do with it and what his hopes would be. He's developed a huge knowledge of the art world and he really could see where he would like to position in it… but David is quite ambitious in some ways. He likes the prestige of it and he's got an ego.* (Sarah)

> *Sam now calls himself an artist and he is very proud of his work.* (Michael)

4.4.1.3 Subtheme 1.3 - Family or caregiver support

Both artists, David and Sam have core support from their caregivers for their art practice as well as daily life activities. Sarah, the caregiver of David, described her support as a sister, "*I um… over period of time… I stepped more into this role, understanding more about what it is…, and caring*

about him in a way as a sister would do". Park, art director from Korean arts organisation D, also explained that the involvement of parents or caregivers of artists with cognitive impairment were critical to maintain and develop the art engagement for the artists:

Most of the parents or caregivers get more proactively involved in supporting and planning for public exhibitions. I can see when the parents or caregivers are positively changed, their positive attitudes also [have a] positive influence on their children.

Figure 4.2 Overview of enablers for developing artistic careers of the artists
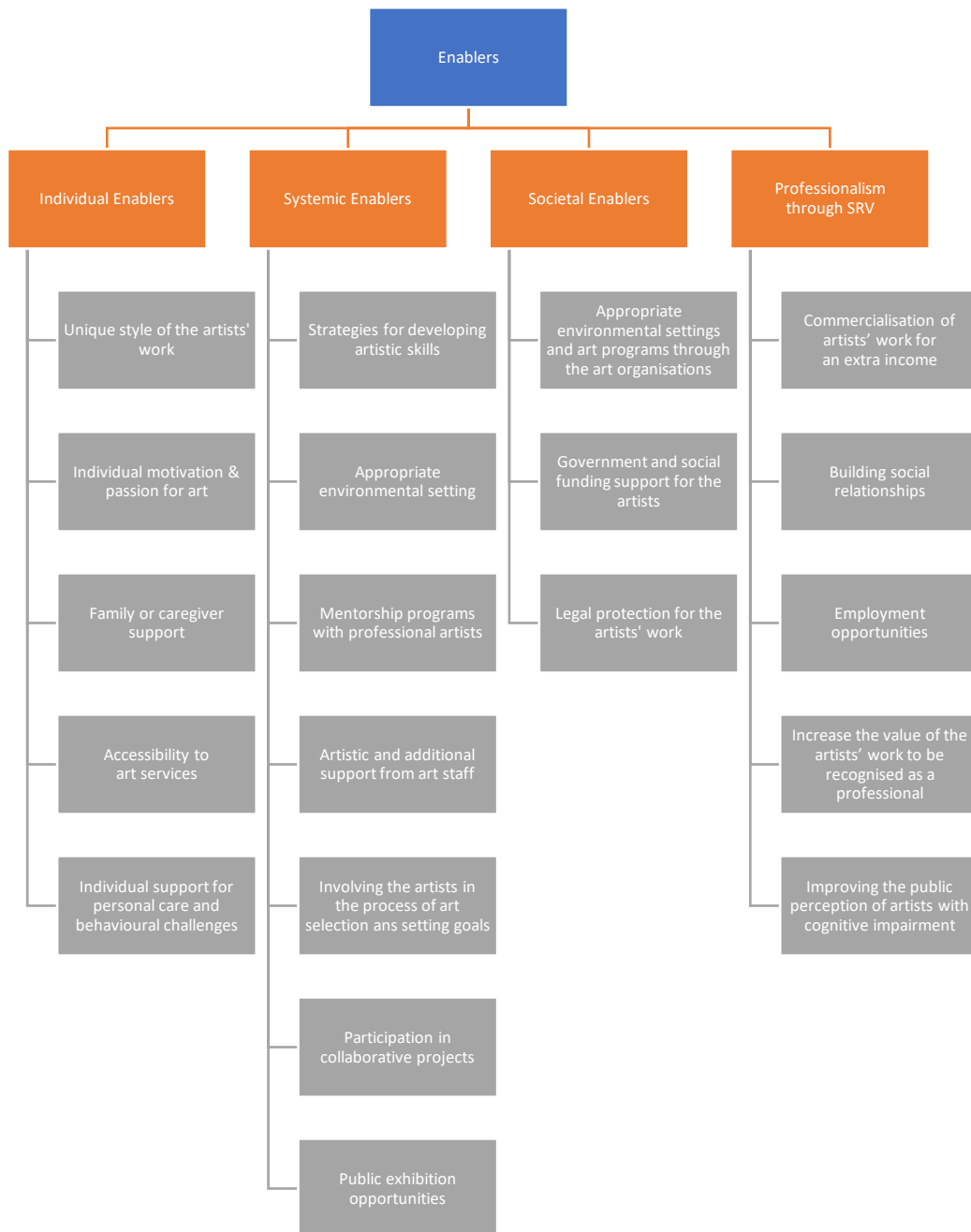
4.4.1.4 Subtheme 1.4 - Accessibility to art services

Both artists, David and Sam, had opportunities to access art organisations on a consistent and regular basis for a long period. Michael talked about the journey of how Sam got involved in art practice at arts organisation B:

> *Sam was fortunately offered a small position at [art organisation B]…. He now attends four days a week at [art organisation B].*

4.4.1.5 Subtheme 1.5 - Individual support for personal care and behavioural challenges

All four art organisations provided appropriate support for individual artists to manage personal care and behavioural challenges if needed. Kim from Korean arts organisation C emphasised benefits of working in partnership with disability organisations: "*We have close relationships with the disability centre…. We can discuss anything or any issues with them… in order to manage personal confidentiality including the information about family, individual conditions of their disabilities etc. This is a critical part of us*".

Tom from arts organisation A also commented on the importance of having basic knowledge of medication and managing autistic behaviours: "*We have epilepsy training and how to deliver the Midazolam and we've all done a workshop around epilepsy and we've done lots of training in workshops around autism and behavioural stuff*".

4.4.2 Theme 2 – Systemic enablers

4.4.2.1 Subtheme 2.1 - Strategies for developing artistic skills

All the art staff and caregivers described that the artists had individualised support for developing their technical skills in their art practice by setting personal goals or individual needs. All four arts organisations did not integrate any teaching type of directing for artistic development. Instead, the art staff focused on individual interests and strengths in their art styles to improve their artistic skills. For example, Jane, an art director for arts organisation A explained the philosophy of directing art for the artists: *"Number two is non-directive philosophy. We don't teach people how to paint and how to draw. It's very much about eliciting [the] person's personal style…. We do help to guide if people need or want to learn technical things like printmaking, ceramics; we will assist in teaching technical things"*.

4.4.2.2 Subtheme 2.2 - Appropriate environmental setting

According to the art staff participants, the artists do not have to follow a set routine in the studio but they are encouraged to take lunch or recess with other artists. Additionally, the artists must use a signing book to record their attendance and their hours spent on creating their artwork.

> *If an artist [with cognitive impairment] doesn't have any idea for their artwork, I will make some suggestion for a topic or a theme. The average time for working on their artwork is an hour and a half, and we all have a recess time for 30 minutes.* (Lee)

> *Only structured things are the sign-in book and, marking the attendance roll, and administering medication and signing the medication chart and… lunch time!* (Emily)

All the art staff also agreed that they provided a relaxed studio atmosphere in order to encourage more independence and to give more freedom of choice for the artists. Additionally, they converse on a regular basis with the artists as they are working on their projects.

> *We [staff] do talk regularly to the artists about their work. Again, it depends on what's happening though. We also work quite organically with the artists and I feel we have a relaxed studio vibe. We discuss things when things require discussion and leave the artists alone to work freely when they need to also. This is what I mean by working organically and being sensitive to an artist's needs.* (Emily)

Kim pointed out that having a respectful attitude and mindset are critical when working with the artists: *"As long as we embrace our differences and could communicate well enough with the artists… and I think that's the most critical attitude."*

All the art staff have qualifications related to art, and they call themselves artists as well. Tom explained that they have opportunities to develop their own professional artistic techniques and knowledge as well as providing behavioural management and/or other required services that the artists' need: *"We will be very flexible when artists have a residency opportunity for professional development opportunity. If there is a professional development opportunity that will benefit the organisation, then there would be a financial aid offered as well; whether it's some amount or a full amount"*.

4.4.2.3 Subtheme 2.3 - Mentorship programs with professional artists

All four art organisations offered opportunities of mentorship with internal and external professional artists for artists with cognitive impairment to develop their art practice.

We don't have any mentorship program at the moment because what we do is a kind of mentoring for them. (Kim)

Art organisation B have various artists in residence, seminars and workshops events, and they have their own special creative talents: *"There are some artists who come voluntarily to mentor…. There are other supporters who are artists."* (Michael)

Sun explained that the artists have opportunities to work with different mainstream artists, but they do not necessarily call them a mentor but a collaborator. According to them, the artists with collaborator artists share their common interests in art and work together sometimes.

So, I would say [the collaborative art program at art organisation D] might be different from a form of mentor and mentee, and their roles and projects are diverse depending on the individual teams. I think in English calling them a 'collaborator' or 'collaborative artist' would be the best way to describe them. (Sun)

Helen and Emily from art organisation B commented on how the mentorship program had brought artistic influence for their artists and the mentorship concept became the seeded idea to set up as an on-going program:

It was that kind of seeded concept that we got funding for which was five of the artists we were working with to get 10 days of bespoke mentorship aligned with mainstream artists. They loved the project…. And then in about 2014, the state government did a huge amount of research with [a university] and they wanted to cultivate more inclusion within art and disability in [a state]… We were able to get further project funding and then that developed into program funding so that we were able to take the seeded idea and have it as a 12-month ongoing program. (Helen)

4.4.2.4 Subtheme 2.4 - Artistic and additional support from art staff

All the art staff described diverse ways of how the art staff engaged with the artists in terms assisting them to develop their art practice and careers. For example, Tom from art organisation A explained that, "*we certainly don't direct the artist. It's all about the artists being encouraged with mentorship and feedback to find their own 'thumbprints'; their own artistic creative voice. We offer [many] opportunities to lead; for them to involve [themselves] in the studio programs and we offer various disciplines in order for them to find that…. We have a lot of goals that we set with, on behalf of, just by the artist about their aspiration, what they would like to achieve with their art practice. From those goals… set, we then try to implement the activities to make the goals achieved*".

Tom also mentioned how he manages the situation with artists when the artists do not get involved in exhibitions or selling their artwork or any challenges even if they want.

> We only have a very small [number] of… issues around 'why don't I and why aren't I in this exhibition' or 'I haven't been in an exhibition', 'No one bought my artwork'. That doesn't happen a lot, which is thank goodness because that would a horrible conversation to have. You can't lie a way out of that. You got to be brutally honest in a conversation: 'Remember we had a chat about this; you know you can make work, but we can't make anyone buy your work'.

Kim, CEO of Korean art organisation C, described her strategies to support artists' development: *"We encourage them to try as many times as possible even if they keep failing with their attempts…. I think the best thing is to give them enough time to try…. So, I try to introduce relevant books depending on their interests".*

4.4.2.5 Subtheme 2.5 - Involving the artists in the process of art selection and setting goals

In terms of making decisions and the artwork selection process, the art staff tried to involve the artists as much as they could, unless the artists did not want to be involved. For example, Kim described the process of selecting artwork and title the artwork: "*He is generally expected to draw three to four illustrations during the given time. During the process of selecting designs, we [art staff] do discuss together by asking him why he titled them [the artwork] as such… or also discuss which one he likes, and we like".* Lee, from Korean art organisation D, added that "*we try to be patient for the artists to make their own decisions".* Emily also described how she usually talked to the artists to prompt their work pace in order to achieve their individual goals:

> On most days I will talk to the artists as a group, as people are working, to let them know if there are particular deadlines that some artists may be trying to achieve, so we can keep focus for those artists.

4.4.2.6 Subtheme 2.6 - Participation in collaborative projects

Results indicated that all the participants agreed that the artists were challenged and achieved increased capacity and new goals through participating in diverse collaborative projects. Park from Korea commented that,

> We try our best to avoid any situation to work in only a one-way process. For example, we had a collaborative project with a clothing company that wants to design some clothes by using the artwork of the artist at [art organisation D]. Then, we didn't just send the profile of the artist, but

we suggested that we would like the artist to get involved in the process of designing through a collaborative art workshop. We attempt to compromise between both parties [companies and the artists] as a mediator.

4.4.2.7 Subtheme 2.7 - Public exhibition opportunities

All four art organisations had provided public exhibition opportunities and collaborative exhibitions with external professional artists or public galleries. For example, Jane and Tom explained how the art staff encouraged the artists to be a part of mainstream art.

Yes, it's one of our goals. It's very important that they are invited to be a part of bigger exhibitions. (Jane)

Works are reviewed by the studio staff during the break the artists have. A selection of the best quality work is taken from that review, and then it goes downstairs and is stored in the artists' work in stock folios. All of the work in this room, a selection from that review is eligible for exhibitions for prizes, competitions and it could be put into the public domain. (Tom)

4.4.3 Theme 3 – Societal enablers

4.4.3.1 Subtheme 3.1 - Appropriate environmental settings and art programs through the art organisations

Results from all staff and caregiver interviews suggest that an appropriate professional art studio environment with skilled artists and not just support workers, that is accessible, meets sensory needs, and is of a professional artistic standard is critical for growth and development of individuals. For example, Tom and Park explained how the studio staff and the artists have influence on each other and how the studio staff create an appropriate environment to engage with the artists.

And then the studio staff have influence on the artists, and they are influenced by their peers. What the great things about having a studio and having this place which is dedicated to artists and being an artist… It would be beneficial, and we need to be accessible as possible. But at the moment, realistically it's quite difficult, so we may provide the artists with noise-cancelling headphones if they need so we need to allow those who need to cut out the noise by music playing. We do little things to adjust the studio, so that we certainly let everybody know who's got sensory stuff like touching. (Tom)

[Art organisation D] is the place where people should freely have interaction, and it is something unique about [art organisation D]. I feel meaningful when I see the artists doing their work with

their own will in the respectful and embracing environment. It is significant when I feel that the artists trust the staff members even though we can't have verbal communication. (Park)

As an enabler, Jane talked about what the art organisation had to change in their programs and systems since NDIS funding was introduced, and she also mentioned that they could create some potential programs for wider communities:

We had to change a few things like face-to-face hours with the artists, we had to extend those to make us financially viable, put an extra program on, but now we are looking at exploring the model of managed growth that might just be providing our expertise to other organisations in terms of structure, frameworks, finance models, it might be creating a sort of remote outreach services.

4.4.3.2 Subtheme 3.2 - Government and social funding support for the artists

All of the art staff participants described the complexity and diversity of accessing resources and income through multiple avenues, and how they maintain financial management with the aim to improve their service and bring benefits for the artists while maintaining good governance.

Currently most of our artists have funding through NDIS…. We charge fees to attend the studio programs, but we also seek a lot of philanthropic grants; artistic grants; government – state and federal government; we rent out our studio and gallery; we take commission on half of the artwork sales. We pull lots of money from lots of different places. (Jane)

Now, we are mainly relying on government funding, social funding from some companies, and we also apply whatever we could fit into… such as social support funding or education funding. Secondly, we receive some donation from groups or individuals, and there is some income through selling our merchandise and membership fee from the artists. (Park)

We have diverse income streams… we generate incomes through selling, leasing and licensing artwork. And then we also have creative experiences that people pay for. (Helen)

4.4.3.3 Subtheme 3.3 - Legal protection for the artists' work

All four art organisations arranged an artist agreement for the artists when they participated in any exhibitions or commercial projects. The art staff commented that the art agreement is critical for protecting the artists' rights and economic benefits. For example, Park explained that "*we prepare a legal agreement and a consent form for using the artwork for any commercial purpose or public*

exhibition because those opportunities are vital for them to make some income. Once we get the signed consent forms back from the artists and their caregivers, we can proceed with the projects".

The art staff also explained what conditions they included in an artist agreement, depending on individual artists and their intention and how it could work effectively for both the artist and the organisations. For example, Park reported that,

In the agreement, we include some personal information like names, DOB and their challenges. The terms and conditions of the membership agreement are quite general, but which are not useful to apply to individual cases. So, we tend to prepare individual contracts depending on different projects. The arrangements are basically following the general terms and conditions of the membership agreement, but also it adds the different condition of profit share depending on each project.

Jane explained that *"whenever an artist starts at [art organisation A], the artist has to sign an agency agreement or a guardian—one of the two. The artist agency agreement outlines everything we do in regard to promoting their artwork selling their artwork licensing fee reproduction fee, so if somebody wants to use an image on our website they need to pay a fee".*

In terms of accessibility to legal advice if required, each of the art organisations did not get a consistent level of legal support. Organisations tended to look for pro bono legal services, including both private and public services. Jane from art organisation A stated that *"we don't get a consistent service, but we look for pro bono [services] where we get it. It changes over time. We got a different organisation and different legal people for different advice".*

4.4.4 Theme 4 – Professionalism through SRV (Social Role Valorisation)

4.4.4.1 Subtheme 4.1 - Commercialisation of artists' work for an extra income
All four art organisations provided opportunities for the artists to commercialise their artwork to make extra income and gain economic benefits. The art staff from both Australian and Korean art organisations described their income through multiple avenues, and how they maintain financial management to improve their service and bring benefits for the artists without taking a high risk.

Commercialising or merchandising from the artwork… we don't produce ourselves, but we have a partnership with the company called [the name of the commercial store]. We always have someone else take the risk. We just get a percentage of sales. The artists get paid the fee for licensing their images. (Jane)

The selected illustration would be to apply to commercial products as a cover design, and the profits from selling the products would be shared to the artist of the illustration. At the moment, between 40% to 50% of the profits are shared to the artists and also partially paid to the non-profit art communities that the artists belong to as a form of support funding. (Kim)

One of the artists [Sam] had his artwork selected to be digitally printed for some lining inside [the name of the fashion brand company] products. Sam's artwork was printed onto silk and they were incorporated into luggage tags, wallets and other products. (Emily)

Kim also described how commercialisation of artwork created by the artists could generate social benefits as well as gaining economic benefits for the artists:

As a product designer, I tried to create innovative and sustainable designs that included the artistic values of artists with cognitive impairment to empower them. This opportunity can offer artists with cognitive impairment [the chance] to participate in socially valued roles in the same way as artists living without a disability. (Kim)

4.4.4.2 Subtheme 4.2 - Building social relationships

All the art staff agreed that the artists not only benefit through developing their artistic careers, but they also benefit from engaging and interacting in a social setting with others in the studio programs. For example, Tom described the studio atmosphere as friendly and encouraging social engagement: "*We only do art but there is a social aspect to the organisation, especially studio because we only have 150 artists across six days a week…. There is one room so there is a really good social aspect; our artists develop quite good friendships and some networks*". Tom also added that the artists have opportunities to participate in wider communities with diverse groups of people in order to improve their social participation.

We give them an opportunity to go out to communities by field trips and bringing a lot of mainstream artists. We try ourselves to connect the guys to a lot of the mainstream art going on whether it's a collaboration or going out to the artist's studio; certainly, mainstream galleries. (Tom)

Park, the art director from Korean art organisation D, and Michael, the caregiver also describes how the artists with cognitive impairment improve their relationship with art staff and others in the studios:

I couldn't see any difference between the art staff and the artists because they worked together no matter [whether] they have disabilities or not. I kind of want to follow that, not necessarily differentiating our roles. (Park)

He [Sam] gets along with the people there, teachers-artists, support staff, and volunteers and his peers well. (Michael)

4.4.4.3 Subtheme 4.3 - Employment opportunities

All of the art organisations in Australia and Korea have been negotiating with the government funding system to accept the art activities of artists with cognitive impairment as employment opportunities. For example, Jane stated that "*I would like to see the NDIS broaden its view of economic participation of employment because at the moment they don't see what we do is building capability in terms of people's employment and economic participation".* Kim from Korean art organisation C explained she has formed two different types of employment opportunities for the artist: "*The relationship between the artists and [art organisation C] can be categorised into two different positions; employment and partnership. Some artists can be employed or partnered, and some artists can be both employed and partnered depending on the project".*

Kim also described her journey of working with the artists and what it means to her when she sees their development in art and social aspects:

I found some socially valued roles for them…. Their roles have been extending gradually. In the beginning, they only did simple tasks like folding papers or drawings…. Now he [an artist with cognitive impairment] is in charge of managing the production team as well. As I have been watching their capabilities continuously developing, now I kind of wonder how far they can grow… and I think the potentials are wide open.

4.4.4.4 Subtheme 4.4 - Increase the value of the artists' work to be recognised as a professional

All the art organisations have tried to increase the value of artwork created by the artists through professional marketing and promotion.

Well, we have a mission which is three things. One is to support artists with intellectual disability, one is to promote their work and third one is to advocate for their inclusion within the broad contemporary art sector. (Jane)

We always acknowledge the artists by printing 'illustration by the name' of the artists on the design of the products. We don't necessarily mention anything about 'disability'. I've always

shared this part of the process with the artists because I wanted to empower them as a professional artist by explaining the significant meaning of 'copyright' imprinted on the products. (Kim)

We worked with an amazing branding company. They helped us to decide on the name… have a very professional logo. The logo can encompass diverse styles of artists. That branding is even in our website and style guidelines that we have…. Our purpose has been about selling artwork and changing perceptions. We've been trying to increase the value of our artists' work and increase the awareness and the audiences. And we've been really [working on] getting the work into the galleries… but particularly getting the work to curated exhibitions where the curator has a good reputation. It's not my job to say the work is great, but we want people in the [wider] world [to] have no interest but to say the work is great. (Helen)

4.4.4.5 Subtheme 4.5 - Improving the public perception of artists with cognitive impairment

All the art staff and the art organisations have tried different approaches in order to emphasise the value of artwork and the artists without using a word 'disability'. For example, Helen, the art director from art organisation B, exhibited the artwork of artists with cognitive impairment without any indication of 'disability': "*Emily and I started to curate shows in contemporary galleries where we didn't use the word, 'disabilities'. We would take more contemporary styles of our work and advertise like you would [in] any contemporary galleries. We got a really good response to the works and the artists love it*". Kim, CEO of a Korean art organisation also stated that "*we don't necessarily promote that the designs of the products are created by artists with 'cognitive impairment'. It is simply because I want the public to see the value of the designs as itself without any sympathy, empathy or prejudice…. I think that it should be the direction to sell the products and values of the artwork created by artists with cognitive impairment without promoting their label of 'disability'.*

Park and Sarah emphasised that their art organisations have intentionally developed their services and art programs to help break down the barriers between outsider art and mainstream art:

I've seen that [art organisation A] has developed too, and they endeavour all the time to break down the barrier of mainstream versus outsider art. (Sarah)

The more we show our work in public, and the public audience would have more opportunities to enjoy our work. So, I think it is essential to extend our networks to broader communities…. If the art society broadens the diversity of art contents, it wouldn't be necessary to differentiate between an amateur and a professional. (Park)

Chapter 5
Discussion

5.1 Introduction

This chapter will discuss three critical findings of this current research study through the perspectives of the insiders (caregivers) and outsiders (art staff) regarding the experiences of two artists with cognitive impairment.

The three findings include:

1) influences on public perception of artists with cognitive impairment;
2) the impact of social structure on artists with cognitive impairment; and
3) the value of employment opportunities based on Social Role Valorisation (SRV) theory.

As the results showed some differences in cultural and social aspects in the responses between the Australian art staff participants and the Korean art staff participants, this chapter will also discuss those differences. The strengths and limitations of the study will be discussed, and recommendations for future research will be made, including the need for an in-depth study on societal infrastructure which includes a legal and policy point of view.

5.2 Critical influence of public perception on artists with cognitive impairment

All the interview participants, including caregivers and art staff from both countries, Australia and South Korea, agreed that one of the biggest challenges faced by artists with cognitive impairment is society's lack of understanding of cognitive impairment, which leads to the general public incorrectly assuming that people with cognitive impairment are 'inadequate' and 'incapable'. According to Park, an art director of Korean art organisation D, during public exhibitions which display artwork created by artists with cognitive impairment, the general public often question if the artists independently created the artwork or if they were supported by professional artists. Park also commented that those *"kind of questions and doubts make the artists and their parent or caregivers very disappointed and feel disgraced"*. Solvang (2018) and Sandahl (2018) also explained that the general public consciously or unconsciously tends to be sceptical about the quality of artistic capabilities if the artists have any disabilities. The studies by (Solvang, 2018; Sandahl 2018; Grant, 2013; Zhuang, 2016; Cachia, 2014) describe public perception as being the most critical challenge for artists with cognitive impairment. For example, art activities for individuals with a disability are predominantly

seen as a recreational and therapeutic pursuit rather than as professional art practice. Helen, an art director from Australian art organisation B, commented that *"what I have found genuinely there is misassumption [that an artist with] intellectual disability can't make good art. There is an assumption that I am an art therapist, but I am not an art therapist".*

Public perception is also interrelated with and influenced by government funding systems and accessibility of art services in both Australia and South Korea. For example, Jane and Helen, art directors at Australian art organisations A and B, advised that the National Disability Insurance Scheme (NDIS) funding tends to view the art practices of artists with cognitive impairment as a component of recreational day options programs. Jane commented that *"I would like to see the NDIS broaden its view of economic participation of employment because at the moment they don't see what we do is building capability in terms of people's employment and economic participation".* Depending on how the art activities of individuals with cognitive impairment are viewed, the funding accessibility and grant opportunities can be varied. Inconsistency of support funding creates limitations in terms of sustaining the art organisations and art services for artists with cognitive impairment as well as art staff. According to both Australian and Korean art staff participants, they had to play multiple roles to manage the art organisations due to a shortage of staff and time. For example, Emily a studio manager for Australian art organisation B reported that *"I am on the floor each day with the artists and lead arts facilitator and managing the studio/volunteers/staff/guest artists and the artists themselves…. We have time challenges and we never have enough time for everything…. We also have other administration work, emails, planning, supply orders and other types of communication for the projects and partnerships the artists are involved with".* Tom, a studio manager, also expressed concern regarding work overload due to the NDIS and a lack of capacity including space and art programs to offer for new artists with cognitive impairment: *"We've never been busier because of the NDIS, new insurance scheme. We've got a growing waiting list, but we got a full capacity".*

One significant finding of the study was the responses received from the Australian participants and Korean participants when responding to a question about the confidence levels of artists with cognitive impairment and their caregivers. Korean art staff members stated that there was a general lack of confidence in both the artists with cognitive impairment and in their caregivers. Indeed, this lack of confidence may be why none of the Korean caregivers agreed to participate in this present research project. According to Kim, CEO of Korean art organisation C: *"Sometimes, some parents or caregivers have a lack of understanding for the disabilities of their children, and they are highly anxious… They often say, 'my child can't do anything due to his/her disabilities.'".* According to Kang

(2010), research studies on the awareness of disability and human rights of people with disability in South Korea found that people with disabilities have been disregarded in most of the social participation areas including education, employment and community activities. On the other hand, the Australian art staff participants or caregivers did not mention a lack of confidence in the artist nor the caregivers. The caregivers stated that their children proudly called themselves artists. The Australian societal systems, including social and government funding and accessibility of art programs, were of a relatively higher quality compared to Korea.

The Australian government showed a more positive attitude in promoting inclusion in social communities by cultivating art and disability in mainstream art compared to the South Korean government. For example, Helen an art director of art organisation B stated that *"in about 2014, the state government did a huge amount of research with [a university] and they wanted to cultivate more inclusion within art and disability in [a state]. We were able to get further project funding and then that developed into program funding"*. Jane also explained that *"currently most of our artists have funding through NDIS…. We charge a fee to attend the studio programs, but we also seek a lot of philanthropic grants, artistic grants, government state and federal government"*. On the other hand, Park and Kim, both art directors of Korean art organisations, agreed that the biggest challenge for them to sustain art organisations for artists with cognitive impairment is to seek funding support. Park reported that *"it is difficult to manage a non-profit community in the Korean social structure. Currently, many communities are set up and managed by parents of people who have disabilities, but those communities have financial difficulties because they don't have enough financial support from the government or society"*. Presenting a lack of confidence in artists with cognitive impairment and their caregivers by only Korean participants is an interesting point to consider, and this phenomenon could also be correlated to the public perception of disability in general, whether the society has inclusive attitudes or not might be seen as a cultural difference.

The current research study found two aspects that have influence on the attitudes of the mainstream towards artists with cognitive impairment. Firstly, the public perception of those with cognitive impairment as being 'incapable' of making good art has significantly impacted on devaluing the artistic achievement of artists with cognitive impairment compared to mainstream art. The other aspect is categorising the art of artists with cognitive impairment as outsider art based on the institutional art definition. Kim, director of Korean art organisation C and Helen, an art director of Australian art organisation B, both agreed that individuals with cognitive impairment have no opportunities to undertake a formal art education to obtain an art degree or qualification. The mainstream art establishment generally requires artists to have formal qualifications in an art area in

order to be recognised as a professional artist (Bain, 2005; Fokt, 2013). According to Kim and Helen, curators and mainstream art staff professionals, they have the misassumption that artists with cognitive impairment are 'incapable' of making good art because those artists are not professionally trained. Park, art director of Korean art organisation D, stated that *"if there is an artist [with cognitive impairment] who wants to be a part of mainstream art, so the artist is developing his skills and working hard to get in there"*. When public perception of artists with cognitive impairment is set on 'incapable', the view tends to influence overall society, impacting on funding, services and social positions for artists with cognitive impairment which focus on recreational or therapeutic art for individual and social well-being (Figure 5.1).

Figure 5.1 Overview of the public perception people with cognitive impairment as 'incapable'
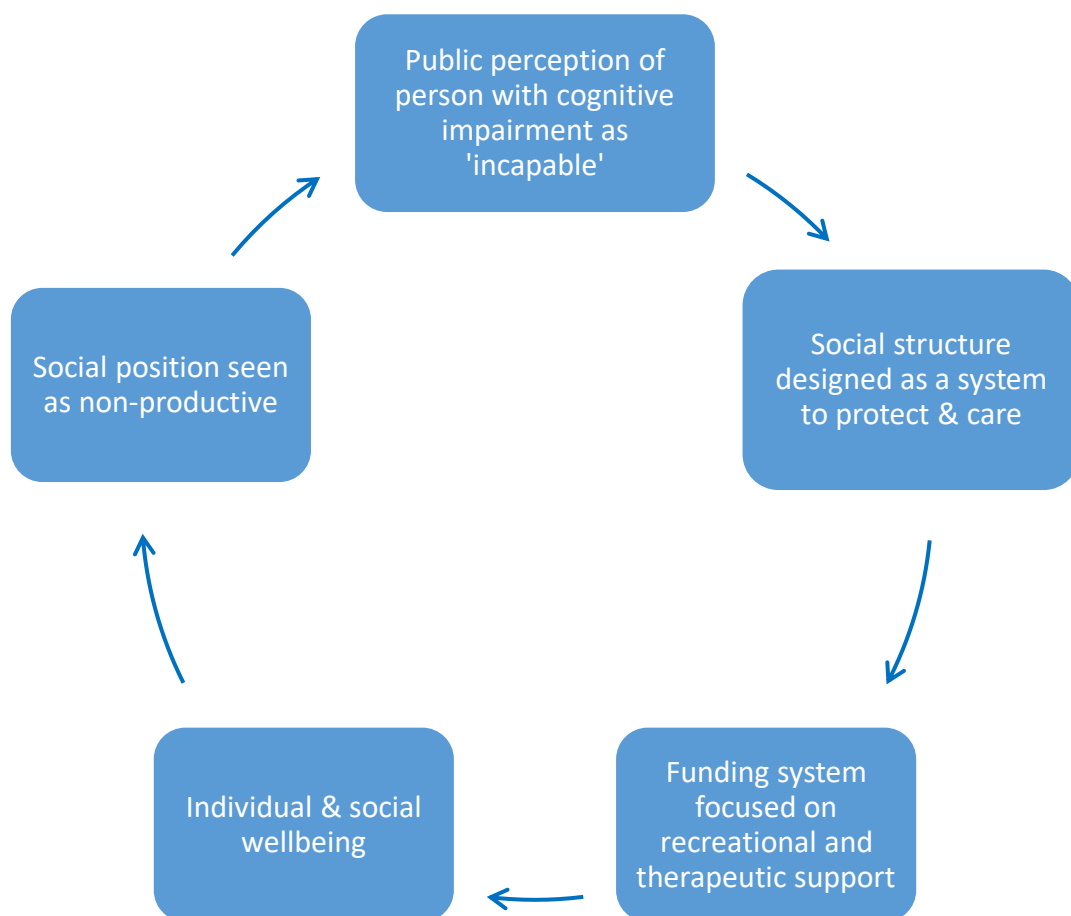
5.3 Impact of social structure on artists with cognitive impairment

Funding support is critical to create and sustain art programs and art organisations in both Australia and South Korea. Depending on how the funding system is designed, it impacts on whether or not individual artists with cognitive impairment can access the art services with appropriate funding support from the government or social funding. The current Australian funding system for disability

is the NDIS, which is individualised funding for people with disabilities to access services and support that they need to improve and sustain a quality life (*National Disability Insurance Scheme Act*, 2013). Both Australian art organisations A and B are registered as NDIS service providers, and artists with cognitive impairment who participate in the art programs are eligible to access NDIS funding to pay for the studio programs (interview with Jane and Helen). According to Michael, Sam's caregiver, the NDIS funding has allowed Sam to have consistent involvement in his art for a long period of time. Consequently, his long-term involvement in art practice and mentorship programs has developed his artistic skills and knowledge to a more professional level (interview with Emily and Helen). Currently, Emily said that Sam's artwork has been commercialised to sell in the public market and online. All four art organisations in both Australia and South Korea have attempted to create more opportunities to develop the artistic capabilities of artists with cognitive impairment. However, the Korean art organisations experience more financial difficulties and challenges when trying to provide appropriate art services for artists with cognitive impairment compared to the Australian art organisations, due to the inconsistency of funding support. This phenomenon is significantly related to social structure for disability, particularly in the funding system and social attitudes.

According to all art staff participants in this current study, social structure needs to create more opportunities for artists with cognitive impairment to transition from recreational art to professional art practice in order to further cultivate art and disability. For example, Australian art organisations A and B provide art programs to develop art careers for artists with cognitive impairment rather than recreational or therapeutic art. However, the capacity of both art organisations is full and there is a long waiting list of new applicants. Jane commented that *"we can't take any more [artists] here – we have 140 artists. We are full. Can't have any more".* Tom added that *"we can still keep and get fresh new talented artists, but it's really hard for us because our artists generally don't leave. We get the right artists, and they enjoy what they do greatly. And if there is anything, they want to come more often than not".* Developing artistic skills and creating opportunities to participate in public exhibitions for artists with cognitive impairment improve the value of their artwork and their social position (Goddard, 2015; Ludwig; 2012; Grant, 2014). Art as therapeutic and recreational activities also provides opportunities to improve social interaction and individual wellbeing for individuals with disabilities (Evans et al., 2017; Darragh et al., 2016; Hackett et al., 2017; Got & Cheng, 2008). However, this current study found that there is still a lack of transition programs from recreational art to professional art for individuals with cognitive impairment who wish to develop their art careers as professional artists in both Australia and South Korea.

5.4 Employment opportunities: SRV

Both artists with cognitive impairment who participated in this study via their proxies including caregivers and the art staff have proved their artistic capabilities through artistic achievement including participating in many public exhibitions, selling their artwork, and commissioning their works through partnerships with commercial companies (Appendix 1). All the Australian and Korean art staff participants, who are also professional artists, recognise the quality of artwork created by artists with cognitive impairment as being as good as the artwork exhibited in contemporary art galleries. Helen said that *"I was really amazed by the high quality of some of the artwork that had been made there [in an art organisation]"*, and she also talked about the positive experience, *"Emily and I started to curate shows in contemporary galleries where we didn't use the word, 'disabilities'. We would take more contemporary styles of our work and advertise like you would in any contemporary gallery. We got a really good response to the works and the artists love it"*.

All the art staff experienced a positive ripple effect when artists with cognitive impairment had productive opportunities to show or sell their artwork in public without using the word 'disability'. According to Kim and Helen, the artwork could be valued without any prejudice or presumption, and consequently, the positive value of the artwork also tends to generate more productive opportunities offered by commercial companies or public galleries, such as licensing images of the artwork or reproduction for selling. This present study found that commercialisation of artwork created by artists with cognitive impairment created economic benefits for the artists. However, the current Australian funding system gets complicated for artists if they earn an extra income. Jane explained that *"it's also complicated by… their pension. If they earn a certain amount they will lose their pension. Our top artist, he doesn't get his pension anymore because he's earning between $5,000-$25,000 a month on his artwork, and which is great. But his mother has to jump through hoops because it's the art world [and] next month he might not sell anything. The income [will] never be consistent"*. Further investigation and changes made to funding policy regarding earning extra income for artists with cognitive impairment is essential in order to improve Social Role Valorisation (SRV) not only for artists with cognitive impairment but also for individuals with disabilities in general. Recognising the art practice of artists with cognitive impairment as an employment opportunity can be an effective way of encouraging SRV, which was introduced by Wolfensberger (1985). SRV strives to create productive opportunities for devalued individuals who might have physical or cognitive disabilities, so they can be considered as valuable members of society by participating in socially valued roles (Wolfensberger, 1985, 1998, 2000, cited Aubry et al., 2013; Caruso & Osburn, 2011). Kim, director of Korean art organisation C, has witnessed the positive effect

of developing the artistic and social capabilities of artists with cognitive impairment by giving them tasks in a socially valued role: "*I found some socially valued roles for them… their roles have been extending gradually. In the beginning, they only did simple tasks like folding papers or drawings… now he [an artist with cognitive impairment] is in charge of managing the production team as well. As I have been watching their capabilities continuously developing, now I kind of wonder how far they can grow… and I think the potentials are wide open*".

All the art staff and the caregivers agreed that artists with cognitive impairment could work in a partnership or mentorship with other professional artists if they could be appropriately supported. They could then be involved in the entire process of collaboration, such as making artwork, deciding titles for the artwork and selecting which artwork they wanted to commercialise or display. For example, Park described his way of managing collaborative works: "*We try our best to avoid any situation to work in only a one-way process. For example, we had a collaboration project with a clothing company that wants to design some clothes by using the artwork of the artist at [art organisation D]. Then, we didn't just send the profile of the artist, but we suggested that we would like the artist to get involved in the process of designing through a collaborative art workshop. We attempt to compromise between both parties [companies and the artists] as a mediator*".

This current study revealed potential benefits and positive outcomes of SRV for artists with cognitive impairment through engaging in partnerships and mentorships with commercial companies or professional artists. Shifting the public perception of artists with cognitive impairment as 'capable' from 'incapable' can generate substantial changes in SRV for the artists (Figure 5.2). If social structure focuses on their artistic strengths and capabilities, the funding system will broaden to support the art practice of artists with cognitive impairment as an employment opportunity. Cultivation of employment opportunities in art and disability could encourage art organisations and commercial companies to work in partnerships with artists with cognitive impairment as well. The experience of two artists with cognitive impairment has shown that productive partnerships or mentorship with professional artists or commercial companies have resulted in economic benefits as well as improving their social image by participating in socially valued roles (Wolfensberger & Thomas, 1981, cited Aubry et al., 2013; Caruso & Osburn, 2011). All the art staff and caregiver participants believed that creating a societal perception of artists with cognitive impairment as valued and productive members of society would potentially improve the public perception of cognitive impairment from 'incapable' to 'productive'.

Figure 5.2 Overview of how building a public perception of artists with cognitive impairment as 'capable' could improve SRV

5.5 Strengths and limitations of the current study

This current research study's strengths include the detailed information obtained from a range of data collected through a number of interviews which were conducted in Australia and South Korea. The semi-structured interview questions based on 'challenges' and 'enablers' guided the interview participants to reveal in depth the experiences of two Australian artists with cognitive impairment in terms of developing their art practice and career as a professional artist. The diverse perspectives from 'insiders' (caregivers) and 'outsiders' (art staff) who have closely worked with the artists with cognitive impairment provided quality information, detailing the challenges, enablers and barriers including individual circumstances, systemic issues and societal perceptions. Four art staff from two Korean art organisations provided comprehensive information regarding the current Korean social

situation and its impact on developing the art practice of Korean artists with cognitive impairment. The information gathered also pointed to cultural and social differences between Korean and Australian society. The rich data collection and analysis supported four criteria for rigour in qualitative research: credibility; dependability; transferability; and confirmability.

Notwithstanding, this current study has several limitations. Firstly, the lack of time and resources, including funding, did not allow the use of an inclusive research process. In addition, attempts to meet the gender balance by including a female artist with cognitive impairment could not be achieved due to the small targeted population. Consequently, the study could not explore any differences or commonality that might be obtained in the experiences between female and male artists with cognitive impairment. Another significant limitation was the travel distance the student researcher had to travel from her home in Adelaide to Sydney, Melbourne and Seoul in South Korea in order to conduct the interviews in person. There was not any research funding available to the student researcher and therefore she had to self-fund her travel to conduct the interviews and site visits in Sydney, Melbourne and Seoul. As the student researcher was only able to make one visit to each organisation, this limited her time to observe the environmental settings and limited her opportunities to build relationships with the artists with cognitive impairment. Despite the limitations, the data collection had quality and richness. Results of data analysis collected from interviews with art staff participants presented a picture of systemic and social barriers that limit the development of art careers for artists with cognitive impairment. For example, some of the significant barriers were related to legal arrangements, such as profit-sharing and licensing agreements, because there are no specific models to follow for legal arrangements for artists with cognitive impairment, especially for those who do not have caregivers or a trusted person to advocate for the artists. Unfortunately, due to the word limit of master dissertations, the results of data analysis for 'systemic and social barriers' could not be included. However, the results of data analysis for 'systemic and social barriers' will be published separately as an academic article.

5.6 Recommendations for future research

The current study introduced a range of 'challenges' and 'enablers', thematically, in order to develop the art practice and careers of two artists with cognitive impairment through exploring the experiences of the participants. Each theme revealed significant issues, such as systemic and societal challenges, which will be worthwhile to investigate in depth to build an effective framework or strategy for the development of art careers or transitioning programs from recreational art to professional art. It would be valuable and beneficial to undertake longitudinal research to explore

funding systems, including the best way for artists with cognitive impairment to manage their disability pension while earning extra income from their art careers. Further research is also needed to ensure disability policy protects the legal rights of artists with cognitive impairment when they can take up the opportunity to commercialise their artwork.

This current qualitative research also found positive outcomes arising from the artists' involvement in mentorship programs along with the potential to commercialise their artwork, which it would be, the researcher asserts, worthwhile to be researched further through rigorous data collection and analysis.

5.7 Conclusion

This current qualitative research study explored the experiences of two Australian artists with cognitive impairment and also explored the perceptions and experiences in relation to their work with people with cognitive impairment of four Australian and four Korean art staff. For several reasons including complex communication challenges of the artists with cognitive impairment; a lack of time to build a relationship with the artists; and focusing on the exploration of systemic and social factors in order to develop an art career for the artists, the semi-structured interview was indirectly conducted by implementing a proxy intervention, which investigates the experiences of how the artists have developed their art practice and career through eyes of caregivers as 'insiders' and art staff as 'outsiders'. The participants described two aspects in great detail, which were the 'challenges' and 'enablers' of the artists' experiences in terms of developing their art practice. The data collected from six Australian participants and four Korean participants were thematically analysed and four main themes emerged: individual; systemic; societal; and pursuit of professionalism, under both 'challenges' and 'enablers'.

Results of data analysis presented useful and practical strategies to further the development of the artists' art practice. The participants also described the limitations they had confronted due to the current social structure. It is the present researcher's opinion that the most critical finding arising from analysis of the interview responses of participants in the current qualitative study, is that it is important to change the general public's perception of cognitive impairment. This is because once society changes their view of artists with cognitive impairment from 'incapable' to 'capable', there will be a vast societal shift, leading to improvement in the wider community and the mainstream art community which will support implementing strategic plans underpinned by the principles of SRV for artists with cognitive impairment as well as other artists with disability in general.

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Appendix 1 Summary of three case studies

Case study 1

About the experience of an artist with cognitive impairment, David

Proxy interview participants

Caregiver: Sarah, a half-sister of David

Art staff: Jane, an art director of Australian art organisation A in Melbourne

                    Tom, a studio manager of Australian art organisation A in Melbourne

About the artist, David

David is both a painter and a ceramic artist. He has been developing his art practice for more than 20 years in an art organisation A in Melbourne. According to his sister, Sarah, David is living with an intellectual disability and autistic traits, so he confronts individual challenges, including health issues, physical issues and concentration. Despite the challenges, he has passion and ambition in his art practice, which becomes his motivation to develop his artistic skills and interests. Tom, a studio manager who has supported David for many years, also added that *"David craves success. This validation is a real motivator for him to keep doing work and to continue progressing his art practice"* (Stonehouse & McDonald, 2014). David has participated in many groups and solo exhibitions, and he also has sold his artwork during the exhibitions. David had different mentors to collaborate with, and he also developed his artistic skills and inspirations through mentorship programs. According to Sarah, David is confident and calls himself a professional artist. Sarah has supported David as a caregiver since his parents died. Tom is a studio manager of art organisation A where David has accessed artistic support and programs for over 20 years.

David's artistic achievement

Currently, David has several artistic streams in his work; digital media, puppet making and painting. He uses both paints and ink, but his favourite medium is ink. He does impressive work with that medium. According to Jane and Tom, David's artwork sells well, and once he sold 15 paintings at one Melbourne art fair in 2012. Tom explained that selling artwork is important for the artists because it is about more than earning extra income but providesvalidation, recognition and signs of success in the broader community. David also sell his ceramic figures through a commercial trade shop in Melbourne which sells art and design products. They sell ceramic figures that David made in the past

as well as tea towels printed his paintings, such as portrait of geisha (one of his favourite art subjects). According to Sarah, David's sister, David had different mentors at different times. He occasionally has one-on-one with a mainstream artist. David joined a program called 'Knowing Me, Knowing You' with a mainstream artist. They drew a portrait for each other. After the program, they grew their relationship as a friendship, so they went to galleries together and spent time together having coffee and chatting about art.

David was selected to go to Glasgow in Scotland to an art project hosted by an international art organisation, so he went with Sarah, Tom and Jane to participate in the project. Artists with cognitive impairment from 10 different countries joined the event and they spent three days together to work on art. According to Sarah, David did an amazing broad painting using acrylic and gauche of the Glasgow skyline. At the end of the event, he had a chance to present his artwork, and he talked about his painting and what it means for him to be an artist at the art organisation A. Sarah said that *"it was the moment he was the most articulate I think"*.

About art organisation A in Melbourne

Art organisation A has aimed to provide excellence in the quality of both exhibitions presented and the studio program as a leader and innovator in the arts and disability sectors over the past 40 years (Stonehouse & McDonald, 2014). Tom has been a leading art supporter for David. Tom shared his experience as a studio manager regarding individual and systemic challenges and enablers for artists with cognitive impairment to develop their art practice. Jane is an art director of art organisation A. According to Tom and Jane, art staff proactively promote artists and their artwork in the broader community, and provide exhibition opportunities in a range of local, national and international galleries as well as being represented in many public and private collections. Art organisation A offers studio programs for more than 140 artists and collaborative opportunities with mentor artists. The studio provides practical and functional artistic supports in a similar way to a tertiary art environment, and each artist develops their own art style, and they communicate an authentic voice through their art. Art staff are also professional artists, and they provide feedback, technical assistance, critical advice and encouragement (Stonehouse & McDonald, 2014). Jane explained the current Australian systems for disability funding, NDIS, social structure, systemic impacts and societal challenges and enablers in terms of the development of art careers for artists with cognitive impairment.

Stonehouse, A. & McDonald, J. (2014), *SO FAR…; Eight Artists/Eight Stories*, Art Project Australia Inc.

Case study 2

About the experience of an artist with cognitive impairment, Sam

Proxy interview participants

Caregiver: Michael, Sam's father

Art staff: Helen, an art director of Australian art organisation B in Sydney

                Emily, a studio manager of Australian art organisation B in Sydney

About the artist Sam

Sam has been actively involved in his art practice for eight years, and he has developed his painting, weaving and sewing skills through mentorship programs at art organisation B in Sydney. According to Michael, Sam's father, Sam, expresses his thoughts and feeling through paintings, colours and textile. Sam is living with down syndrome, and he has challenges in articulating his thoughts and ideas. However, Michael said that those challenges did not interfere with Sam's passion for learning new artistic skills. Michael described that Sam is shy and reserved, introverted in nature, until he gets to know people. However, he becomes quite cheeky once he gets to know people. Michael said that *"Helen (Art Director) and Emily (Studio Manager) believe he has some talents. They've been helpful with what he has done and have had Sam involved in workshops with different people"*. Sam has been involved in different commissioned art projects including collaborating with commercial companies in Sydney, and his textile has been commercialised and sold in the fashion market. Sam makes some extra income through selling his artwork, including paintings and textiles, but the primary resource of funding support for his art practice is the NDIS funding. Michael described different individual and systemic challenges and enablers in order to improve his artistic capabilities, and he also shared a few of his concerns regarding financial management and accessibility to art program services for Sam. According to Michael and two art staff, Sam has also developed his social relationship with internal and external mentors as well as other artists who have diverse disabilities in the studio.

Sam's artistic achievement

Helen and Emily described that Sam has confidence in mark making and rich scribbles with personality. The patterns Sam created make clear communication through code and reference. Sam has strength in painting abstracts which express Sam's thoughts and energy. Sam is also a proficient weaver. He weaves by blending colours and creating patterns to compose textile wall pieces, sculptures and cushions. In 2016, Sam collaborated with two street-wear designers on a line of

bomber jackets, which featured his original artwork of weaving. According to Emily, Sam collaborated with a painter to create a painted installation as part of an Arts Festival in Sydney.

About art organisation B in Sydney

Helen is an art director of Australian art organisation B in Sydney, which is purportedly formed as a type of social enterprise aiming for creating economic benefits through the art practice of artists with cognitive impairment rather than a recreational art studio. Helen described the journey of establishing art organisation B: *"It was that kind of seeded concept that we got funding for which was five of the artists we were working with to get 10 days of bespoke mentorship with mainstream artists…The project was incredibly successful and we had a show at the end with our artists and mentor artists. The show was received so well. That was 2011. We still have relationships with all the mentors, and the funding body which was the state arts funding body".* The seeded concept of mentorship programs to develop art careers for artists with cognitive impairment was extended to a 12-month ongoing program since the state government decided to invest in research for cultivating art and disability in 2014. This program made the artists with cognitive impairment to step outside from the recreational program of [the other art organisation]. Helen emphasised the need and the importance of professional art studio environment which in a similar way of a mainstream art studio. She stated that *"If they didn't have a disability, they would've gone to an art school most likely, and they might've met peers, such a critical outcome to attending art schools is the networks you get. It's not disability development, and It's like endorsement happens."* Art organisation B aims to provide opportunities to promote the value of artwork created by artists with cognitive impairment by branding, marketing and commercialising their artistic strength.

Emily is a studio manager of the art organisation B who provides artistic support as well as administration services for artists with cognitive impairment. Helen and Emily have visions to improve the public perception of artists with cognitive impairment and the value of the artwork created by the artists through branding, commercialising and exhibiting their artwork without using the word 'disability'. The art organisation B is an innovative art studio which aims to develop the art careers of artists with cognitive impairment as a professional artist. They have actively integrated mentorship programs between external artists and artists with cognitive impairment, so they influence each other in terms of developing artistic inspiration and skills. Helen and Emily described the strategies and philosophy of the organisation, and they also shared their experiences of working with Sam and other artists with cognitive impairment about challenges and enablers.

Case study 3

Exploring the experiences of four Korean art staff from two different Korean art organisations who have worked with Korean artists with cognitive impairment

Interview participants

Korean art organisation C: Kim, a CEO

Korean art organisation D: Park, an art director

                                 Lee, a graphic designer

                                 Sun, a studio manager

Korean Art Organisation C

Korean art organisation C is a social enterprise for making inclusive and sustainable design products, such as paper bookstands, diaries, journals, paper lamp with a solar panel by using recycled paper. The company had an award for social influence from the Korea Social Enterprise Promotion Agency. The company has employed artists with cognitive impairment as well as worked with artists with cognitive impairment as a partnership. Kim is CEO of art organisation C, who has much experience working in the commercial design industry as a graphic and product designer. She attempted to implement the ideas of employing artists with cognitive impairment and developing their artwork for product designs without using the word 'disability'. Kim has experimented with different ways of collaborating with artists with cognitive impairment regarding their challenges and strength. She has been an advocate for progressing of artistic development and economic benefits for artists with cognitive impairment since she has worked with the artists with cognitive impairment. Kim described the journey of making progress with artists with cognitive impairment, and she also explained what challenges and enablers the artists have experienced through developing their art practice. Kim has presented the sustainable products which the company designed with the artwork of artists with cognitive impairment in design events and conferences in South Korea, France and New York without revealing the identities of the artists who designed the covers of the products. She aims to improve the public perception of artists with cognitive impairment and to promote their artistic capabilities to the public audience. Kim also focuses on social impact of creating employment opportunities for artists with cognitive impairment, and she explained economic and social benefits of artists with cognitive impairment participating in productive and socially valued roles. Kim also shared the overview of the company structure and management, and she described challenges and enablers for artists with cognitive impairment from the perspective of an employer.

Korean Art Organisation D

Korean art organisation D is a non-profit art studio that aims to provide studio art programs and collaborative art programs for Korean artists with cognitive impairment. Park, an art director, described the relationship between art staff and artists with cognitive impairment as partners who share the same artistic visions and goals. The artists and the art staff call each other 'creator' to indicate their equal relationships as an artist in the studio. Sun as a studio manager shared her personal experience of working with the artists with cognitive impairment as well as managing the studio in terms of individual, systemic challenges but she also commented on what enablers have influenced on the development of the artists' careers, behaviours and social relationship. Lee is a graphic designer who has worked in the organisation to support the artists as well as making promotional materials or goods for the studio and the artists. She also worked as a mediator artist to support artists with cognitive impairment when they had to collaborate with commercial companies or external artists. Lee shared her perspectives on the public perception of cognitive impairment and disability in Korean society, and she also commented on the legal rights, including copyrights, intellectual property and the public understanding towards ownership of the artwork. She described the lack of public understanding of cognitive impairment and ownership of artwork in general. Park explained the entire system and management of art organisation D, and he also described societal challenges in Korean social structure on disability. Korean art organisation D had much experience of working partnerships with commercial companies, commercialising artwork as a range of products, public exhibitions and collaboration with professional artists from the mainstream art community for artists with cognitive impairment. All art staff shared their knowledge and experience of challenges, enablers, potentials and barriers in order to develop the artistic capabilities of artists with cognitive impairment.

Appendix 2 Overviews of challenges and enablers

Table 3 Overview of challenges for developing artistic careers of the artists

Theme 1 **Individual challenges**	1.1 Physical health and mental challenges
	1.2 Communication and behavioural challenges
	1.3 A lack of confidence in both artists and their caregivers

Theme 2 **Systematic challenges**	2.1 Searching for funding support
	2.2 Financial management for the individual artists
	2.3 Interrelationship between the government funding and extra income
	2.4 Meeting the demands of clients and new applicants
	2.5 A lack of space to create an appropriate environment for the artists
	2.6 Multiple duties for limited art staff members

| Theme 3 **Societal challenges** | 3.1 Public perception towards artists with cognitive impairment |
| | 3.2 Attitudes of mainstream art communities |

| Theme 4 **Pursuit of professionalism** | 4.1 Difficulty of understanding the artists' intent for their art practice |
| | 4.2 Diverse interpretations of professionalism in art |

Table 4 Overview of enablers for developing artistic careers of the artists

Theme 1 **Individual enablers**	1.1 Unique styles of the artists' work
	1.2 Individual motivation and passion for art
	1.3 Family or caregiver support
	1.4 Accessibility to art services
	1.5 Individual support for personal care and behavioural challenges

Theme 2 **Systematic enablers**	2.1 Strategies for developing artistic skills
	2.2 Appropriate environmental setting
	2.3 Mentorship programs with professional artists
	2.4 Artistic and addtional support from the art staff
	2.5 Involving the artists in the process of art selection and setting goals
	2.6 participation in collaboration projects
	2.7 public exhibition opportunities

Theme 3 **Societal enablers**	3.1 appropriate environmental settings and art programs
	3.2 Government and social funding support
	3.3 Legal protection for the artists' work

Theme 4 **Professionalism through SRV**	4.1 Commercialisation of the artists' work
	4.2 Employment opportunities
	4.3 Building social relationships
	4.4 Increasing the value of the artists' work to be recognised as a professional
	4.5 Improving the public perception towards artists with cognitive impairment

Appendix 3

Key studies reviewed in chronological order

Authors	Year	Title	Participants	Method	Findings
Vick, R. & Sexton-Radek, K.	2008	Community-Based Art Studios in Europe and the United States; A Comparative Study	7 art therapists and art staff in Europe 8 art therapists in US	Quantitative research; Survey research method (A four-page, multi-item electronic survey	Comparing art services and programs between Europe and US regarding benefits from artistic participation, funding system and motivations for individuals with intellectual disabilities. US-motivation of art practice focusing on 'treatment' Europe-participants pursue art career, the production of quality art/trends of 'not art therapy' Employment opportunity through art practice is necessary for SRV.
Ludwig, E	2012	Stigma in the Arts; How Perceptual Barriers Influence Individuals' with Disabilities Participation in Arts Organisations	28 art administrators	Quantitative research; Electronic Survey	Art administrators were optimistic about the quality and reasonable accommodations they provided for individuals with disabilities. It also finds that the discrimination experienced by people with disabilities affected their family, providers and other associated with the people. Stigma's effect on participation in the arts is a multifaced problem with roots in societal attitudes. The study suggested a way of eliminating barriers for individuals with disabilities through addressing misconceptions and prejudice about disability, increasing understanding of the requirements of different disabilities, and presenting people with disabilities as customers rather than problems.
Solvang, P. K	2012	From identity politics to dismodernism? Changes in the social meaning of disability art	30 individuals who identified as related to disability art, either by themselves or by disability culture activists, curators and other artists	Qualitative research; interview by using an interview guide	It discussed diverse interpretations of 'disability art' and the barriers for artists with disabilities to be a part of the mainstream art. Disability identity politics is related to the development of disability as a socially and culturally recognised category. Disability art is primarily a vehicle for disabled people in their fight against oppression. The label "disability art" can be blurred and the aesthetic possibilities come into the forefront.

Grant, C.	2014	Participating in arts-and cultural-sector governance in Australia; Experiences and Views of people with disability	32 individuals who identify themselves as artists, art practitioners or art administrators	Mixed Method; quantitative & qualitative research – online survey (Survey Monkey), by phone, assistance from Access Arts Queensland	Factors enabling governance participation; Accessible meeting venue Financial support for participating in governance Disability awareness training for the art organisations Communication provided in alternative format Personal benefits, challenges and barriers were discussed; Having voice Lack of mentorship opportunities
Nyqvist, H. K. & Stjerna, M. L.	2017	Artistry and disability-Doing art for real? Affordances at a day activity centre with an artistic profile	11 participants who live with disabilities	Qualitative research; observation & interview	Participants with disabilities have productive opportunities rather than focusing on recreational or therapeutic art; Creating art as work Participating in public exhibitions Working as an artist Involving in art projects and the development of artistic skills and knowledge
Chandler, E., Changfoot, N., Rice, C., Lamarre, A. & Mykitiuk, R.	2018	Cultivating disability arts in Ontario	Reviewing 300 multimedia stories led by disability-identified artists	Re-Vision; art-based research workshop – multimedia storytelling workshops and theatre workshops with deaf and disabled people/mobilise art-based approaches	Re-Vision workshop had brought non-disability identified researchers and disability artists to develop accessible methods for storytelling through digital and performances. The storytelling disclosed different experiences of artists with disabilities including bias, differences, diverse perspectives of normalcy and the cultural and political importance of creating accessible incubator spaces for artists with disability and hearing impairment

Richards, M., Lawthom, R & Runswick-Cole, K.	2019	Community-based arts research for people with learning disabilities; Challenging misconceptions about learning disabilities	40 individuals with learning disabilities (28-65 years old)	Qualitative research; observation by using photographic research – inclusion and participation community-based research for 12 months at 45 workshops (3 hours per week)	Community-based art project was conducted to tell sotries about different aspects of the participants' lives. People with learning disabilities needed alternative forms of communications and accessibility. Using creative and visual method for the participants eliminated their ideas and their perspectives on cultures, daily life and sexuality. The outcome of the research were exhibited to show communities, and the exhibitions challenged some of misconception related to learning disabilities, such as incapable to work or have creative thinking.
Walker, T., Mitchell, P. & Dlouhy, S.	2019	Cultivating Passion through Collaborative Art; A Dialogic Exploration of Disability Storytelling and Social Change	1 art director 1 operation director	Qualitative; interview-based exploration of one collaborative community arts centre	This arts centre implemented an asset-based approach titled 'Creative Abundance Model' in the art programs for people with disabilities. It found benefits of using 'Creative Abundance Model' to make productive and creative outcomes, which challenge societal ideas of 'normal' to be reconsidered. 'Creative Abundance Model' introduced one way to address new rules and transform art programs; how to foster social change through creative storytelling; how the art-making at the studio allows people to pursue their unique passions.

Appendix 4 Letter of introduction

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30th September 2018

LETTER OF INTRODUCTION

Dear Sir/Madam

This letter is to introduce Jung Yoon who is a research student undertaking the Graduate Diploma in Research Methods in the College of Nursing and Health Sciences at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of *"Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment.*

She would like to invite you to assist with this project by agreeing to be involved in an interview which covers certain aspects of this topic. No more than 1 hour on one occasion would be required.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make a digital audio recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 08 8201 3422, fax 08 201 3436 or e-mail caroline.ellison@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely

Assoc Prof Caroline Ellison

Research Supervisor

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College of Nurse and Health Sciences

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> This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8168). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix 5 Information for Australian participants

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INFORMATION SHEET
For art directors/mentors/staff/volunteers in Rawside, Grape Lab.

Title: "Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment.

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Description of the study
This study is part of the project titled "Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment.

This project will explore personal experiences of artists with cognitive impairment who have been making artistic progress to develop their art career as a professional in terms of individual and

social challenges, enablers and barriers that they have encountered. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

This project aims to develop a depth of understanding of individual challenges, enablers and social barriers in terms of developing art careers as a professional for artists with cognitive impairment.

What will I be asked to do?

You are invited to attend a one-on-one interview with a researcher who will ask you a few questions relating to your perspective about the artists with cognitive impairment in terms of their journey overcome any challenges but also supports they have had to make their artistic progress.

The artists will be informed about the participation in the research project. Once they agree to be involved in the research project, the artist and the caregiver will have consent forms to sign under the artists' agreement before interview dates. The artists will provide their information and discuss their feelings and thoughts through their carers or family. Consequently, they will be participating in the project indirectly. You will provide information to researchers on their behalf.

The consent forms will be handed out to you at least a few days prior to interview dates with the researcher. Once both the artists and the caregivers agree to the participation in the research, you can decide to be a part of the participation in the research as well.

Participation is entirely voluntary. The interview will take between 90-120 minutes. If the interview requires more than the given time, the time could be extended through negotiation with individual participants. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file and which will only be destroyed if the transcript is checked by the participant.

What benefit will I gain from being involved in this study?

The sharing of your experiences will be valuable information to help researchers and art participants or emerging artists with cognitive impairment who aim to develop their art career.

Your experience and perspective will provide practical information to outline what strategies and social supports will be needed to develop art careers as a professional artist for current and potential art participants with cognitive impairment.

Will I be identifiable by being involved in this study?

We do not need your name. Any identifying information will be removed, and your comments will not be linked directly to you. However, due to the small population of artists with cognitive impairment, the participants may not be completely anonymous even though no identifying information will be published. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced, please contact 'Seoul Psychological Support Centre' for support /

counselling that are local and/or accessible free of charge by all local participants. If you have any concerns about anticipated or actual risks or discomforts, please raise them with the researcher.

Seoul Psychological Support Centre

Online inquiry link http://www.psy-supporter.or.kr/online_new/inquiry.asp

Contact number: +82 2 2144 1192

Email: admin@psy-supporter.or.kr

How do I agree to participate?

Participation is voluntary. You may answer 'no comment' or refuse to answer any questions, and you are free to withdraw from the interview at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate, please read and sign the form and send it back to me via email yoon0037@flinders.edu.au

How will I receive feedback?

On project completion, outcomes of the project will be given to all participants via email / post / website.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8168)
For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

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CRICOS Provider No. 00114A

INFORMATION SHEET
For family/primary carers of artists with cognitive impairment including ASD, intellectual or mental disabilities

Title: "Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment.

Researcher(s)
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Supervisor(s)
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Description of the study
This study is part of the project titled "Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment.

This project will explore personal experiences of artists with cognitive impairment who have been making artistic progress to develop their art career as a professional in terms of individual and social challenges, enablers and barriers that they have encountered. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study
This project aims to develop a depth of understanding of individual challenges, enablers and social barriers in terms of developing art careers as a professional for artists with cognitive impairment.

What will I be asked to do?
You are invited to attend a one-on-one interview with a researcher who will ask you a few questions relating to your perspective about the artists with cognitive impairment in terms of their journey overcome any challenges but also supports they have had to make their artistic progress.

The artists will be informed about the participation in the research project. Once they agree to be involved in the research project, the artist and you as a caregiver will have consent forms to sign under the artists' agreement before interview dates. The artists will provide their information and discuss their feelings and thoughts through their carers or family. Consequently, they will be participating in the project indirectly. You will provide information to researchers on their behalf.

The consent forms will be handed out to you as a caregiver at least a few days prior to interview dates with the researcher. This will give you sufficient time to discuss the research project and present the consent form to the artists in a relaxed manner and in a familiar environment to avoid potentially causing anxiety in the artists.

Participation is entirely voluntary. The interview will take between 90-120 minutes. If the interview requires more than the given time, the time could be extended through negotiation with individual participants. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file and which will only be destroyed if the transcript is checked by the participant.

What benefit will I gain from being involved in this study?
The sharing of your experiences will be valuable information to help researchers and art participants or emerging artists with cognitive impairment who aim to develop their art career.

Your experience and perspective will provide practical information to outline what strategies and social supports will be needed to develop art careers as a professional artist for current and potential art participants with cognitive impairment.

Will I be identifiable by being involved in this study?
We do not need your name. Any identifying information will be removed, and your comments will not be linked directly to you. However, due to the small population of artists with cognitive impairment, the participants may not be completely anonymous even though no identifying information will be published. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

2

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced, please contact 'Seoul Psychological Support Centre' for support / counselling that are local and/or accessible free of charge by all local participants. If you have any concerns about anticipated or actual risks or discomforts, please raise them with the researcher.

Seoul Psychological Support Centre

Online inquiry link http://www.psy-supporter.or.kr/online_new/inquiry.asp

Contact number: +82 2 2144 1192

Email: admin@psy-supporter.or.kr

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How will I receive feedback?

On project completion, outcomes of the project will be given to all participants via email / post / website.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

3

Appendix 6 Information for Korean participants
Art Staff

Caroline Ellison
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CRICOS Provider No. 00114A

INFORMATION SHEET
발달장애를 가진 예술가들의 예술적 지원 또는 지도를 하시는 예술가 또는 예술 단체 직원
또는 지원자 분들을 위한 연구관련 정보 – Rawside, Grape Lab. Design

Title: "장애란 꼬리표 뗀, 작품 그 자체로의 인정", 발달장애를 가진 예술가들의 전문
예술가로서 대중의 인식을 향한 예술적 진보와 경험을 연구

Researcher(s)
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Supervisor(s)
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연구과제 설명
이 연구조사는 "장애란 꼬리표 뗀, 작품 그 자체로의 인정", 발달장애를 가진 예술가들의 전문 예술가로서
대중의 인식을 향한 예술적 진보와 경험을 연구에 관한 것입니다.

이번 연구조사는 발달장애를 가진 예술가 분들의 예술 활동에 관한 개인적인 경험과 사회적 또는 개인적인
어려움들에 관해서 탐구하고 어떻게 더 나은 예술활동 할 수 있는 환경으로 개선해 나아가야 하는지에 관하여
연구하는 과제입니다. 이 연구과제는 남 호주에 위치한 플린더스 대학교, 간호 보건 학과의 조력을 받아서
진행되어집니다.

연구 조사 목표

이번 연구조사는 발달장애를 가진 예술가 분들의 전문 예술가로서 발전해 나아가는 과정, 개인적인 어려움과 성공적 요인 등에 대한 이해도를 향상 하려는 목표를 가지고 있습니다.

조사 참여자는 어떠한 질문을 받게 되나요?

인터뷰는 일대일로 조사원과 함께 진행됩니다. 인터뷰는 예술 단체 또는 개인적으로 지원 중이신 발달 장애 예술 작가님께서 어떠한 과정과 지원을 통해서 예술 활동을 지속 가능하게 하는 것인지에 관한 예술 지원 팀 또는 작가님의 견해에 관해 질문 할 것입니다.

조사 참여는 전적으로 자율적입니다. 인터뷰는 90-120 분 소요를 예상합니다. 만약 인터뷰 시간이 부족할 경우 조사원과 조사 참여자 분과 함께 상의하여 시간 연장을 결정할 것입니다. 인터뷰 내용은 보다 정확한 기록을 위해서 오디오 녹음을 할 것입니다. 녹은 내용은 속기록 될 것이며 기록 문서는 조사 참여 분에게 보내서 확인 검증을 받을 것입니다. 녹음 기록문은 안전하게 보관되었다가 논문 기재 후에는 폐기 조치 될 것 입니다.

조사에 참여하면 참여자에게 어떠한 이익이 있나요?

조사 참여를 통해 나누어 주신 참여 자분의 값진 경험은 이번 연구자들이 발달장애인분들의 예술적 참여 또는 발달 장애인 예술 작가님들의 예술 활동을 더 나은 환경과 지원에서 지속해 나아 갈 수 있는 연구자료를 만들어 나아가는데 상당한 기여를 하실 수 있습니다.

조사 참여자 분들의 소중한 경험과 견해는 실질적인 정보 또는 현황을 알려주시므로 앞으로 어떠한 사회적 지원과 계획이 발달 장애 예술 작가님들을 위한 구체적 방책 마련에 도움을 주실 수 있습니다.

조사 참여 중 개인적 정보 또는 신원 보호는 되나요?

조사 참여 중 성함 또는 어떠한 개인 정보는 요구하지 않을 것입니다. 참여자 분에 관해 신원 확인 가능한 정보는 모두 제외 될 것입니다. 다만, 어떠한 개인 신원 정보를 논문에 기재 하지 않음에도 불구하고, 활동 중인 발달 장애인 예술 작가님들의 수가 많이 않음으로, 참여자 분의 신원이 완벽하게 미상이 되지 않을 수도 있음을 알려드립니다. 모든 참가자 분들의 정보와 결과물들은 안전하게 연구자들에 의해 보호 될 것 입니다.

조사 참여 중 어떠한 우려나 피해가 올 수 있나요?

이번 연구 조사원들은 조사 참여자들의 우려가 발생할 수 있다고 예상하고 있습니다. 개인적인 경험을 나눈 과정에서 감정적인 우려나 불편함을 느끼실 수 있습니다. 만약, 조사 참여 후 또는 과정에서 참여자 분들 중 감정 또는 정신적 불편함을 경험하신다면, '라이프라인 (LifeLine)' 상담 (+61 131 114)에 연락하실 수 있습니다. 상담은 무료입니다. 혹시 우려되는 상황이나 문의하실 내용이 있으시다면, 언제든지 연구 조사원들에게 연락 하실 수 있습니다.

조사 참여는 어떻게 할 수 있나요?

조사 참여는 전적으로 자율적입니다. 조사 질문 중에 답변을 거부하시거나 '의견 없음'을 제시 할 수 있습니다. 인터뷰 중에 언제든지 참여 중단 또는 거부를 행할 수 있고 그에 대한 어떠한 불이익이 없음을 알려드립니다. 참여 동의서 작성 후 서명을 하셔서 이메일로 담당 연구 조사원에게 보내주시면 됩니다. 이메일 주소는 아래와 같습니다

yoon0037@flinders.edu.au

조사 참여 후기는 어떻게 알 수 있나요?

연구조사 마감 후, 연구 결과에 대한 내용은 모든 조사 참여자 분들에게 이메일 또는 우편으로 보내드릴 것입니다. 연구 조사 관련 정보 내용을 읽어 주셔서 감사합니다. 조사 참여에 관한 초대에 응해 주실 것을

바랍니다.

3

Parents/Primary Carers

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CRICOS Provider No. 00114A

INFORMATION SHEET
발달장애를 가진 예술가들의 가족 또는 보호자분들을 위한 연구관련 정보

Title: "장애란 꼬리표 떼, 작품 그 자체로의 인정", 발달장애를 가진 예술가들의 전문 예술가로서 대중의 인식을 향한 예술적 진보와 경험을 연구

Researcher(s)
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연구과제 설명
이 연구조사는 "장애란 꼬리표 떼, 작품 그 자체로의 인정", 발달장애를 가진 예술가들의 전문 예술가로서 대중의 인식을 향한 예술적 진보와 경험을 연구에 관한 것입니다.

이번 연구조사는 발달장애를 가진 예술가 분들의 예술 활동에 관한 개인적인 경험과 사회적 또는 개인적인 어려움들에 관해서 탐구하고 어떻게 더 나은 예술활동 할 수 있는 환경으로 개선해 나아가야 하는지에 관하여 연구하는 과제입니다. 이 연구과제는 남 호주에 위치한 플린더스 대학교, 간호 보건 학과의 조력을 받아서 진행되어집니다.

연구 조사 목표

이번 연구조사는 발달장애를 가진 예술가 분들의 전문 예술가로서 발전해 나아가는 과정, 개인적인 어려움과 성공적 요인 등에 대한 이해도를 향상 하려는 목표를 가지고 있습니다.

조사 참여자는 어떠한 질문을 받게 되나요?

인터뷰는 일대일로 조사원과 함께 진행됩니다. 인터뷰는 보호자님 또는 부모님께서 보호 지원 중이신 발달 장애 예술 작가님께서 어떠한 과정과 지원을 통해서 예술 활동을 지속 가능하게 하는 것인지에 관한 보호자님의 견해에 질문 할 것입니다.

조사 참여는 전적으로 자율적입니다. 인터뷰는 90-120 분 소요를 예상합니다. 만약 인터뷰 시간이 부족할 경우 조사원과 보호자님과 함께 상의하여 시간 연장을 결정할 것입니다. 인터뷰 내용은 보다 정확한 기록을 위해서 오디오 녹음을 할 것입니다. 녹은 내용은 속기록 될 것이며 기록 문서는 조사 참여 분에게 보내서 확인 검증을 받을 것입니다. 녹음 기록문은 안전하게 보관되었다가 논문 기재 후에는 폐기 조치 될 것 입니다.

조사에 참여하면 참여자에게 어떠한 이익이 있나요?

조사 참여를 통해 나누어 주신 참여 자분의 값진 경험은 이번 연구자들이 발달장애인분들의 예술적 참여 또는 발달 장애인 예술 작가님들의 예술 활동을 더 나은 환경과 지원에서 지속해 나아 갈 수 있는 연구자료를 만들어 나아가는데 상당한 기여를 하실 수 있습니다.

조사 참여자 분들의 소중한 경험과 견해는 실질적인 정보 또는 현황을 알려주시므로 앞으로 어떠한 사회적 지원과 계획이 발달 장애 예술 작가님들을 위한 구체적 방책 마련에 도움을 주실 수 있습니다.

조사 참여 중 개인적 정보 또는 신원 보호는 되나요?

조사 참여 중 성함 또는 어떠한 개인 정보는 요구하지 않을 것입니다. 참여자 분에 관해 신원 확인 가능한 정보는 모두 제외 될 것입니다. 다만, 어떠한 개인 신원 정보를 논문에 기재 하지 않음에도 불구하고, 활동 중인 발달 장애인 예술 작가님들의 수가 많지 않음으로, 참여자 분의 신원이 완벽하게 미상이 되지 않을 수도 있음을 알려드립니다. 모든 참가자 분들의 정보와 결과물들은 안전하게 연구자들에 의해 보호 될 것 입니다.

조사 참여 중 어떠한 우려나 피해가 올 수 있나요?

이번 연구 조사원들은 조사 참여자들의 우려가 발생할 수 있다고 예상하고 있습니다. 개인적인 경험을 나눈 과정에서 감정적인 우려나 불편함을 느끼실 수 있습니다. 만약, 조사 참여 후 또는 과정에서 참여자 분들 중 감정 또는 정신적 불편함을 경험하신다면, '라이프라인 (LifeLine)' 상담 (+61 131 114)에 연락하실 수 있습니다. 상담은 무료입니다. 혹시 우려되는 상황이나 문의하실 내용이 있으시다면, 언제든지 연구 조사원들에게 연락 하실 수 있습니다.

조사 참여는 어떻게 할 수 있나요?

조사 참여는 전적으로 자율적입니다. 조사 질문 중에 답변을 거부하시거나 '의견 없음'을 제시 할 수 있습니다. 인터뷰 중에 언제든지 참여 중단 또는 거부를 행할 수 있고 그에 대한 어떠한 불이익이 없음을 알려드립니다. 참여 동의서 작성 후 서명을 하셔서 이메일로 담당 연구 조사원에게 보내주시면 됩니다. 이메일 주소는 아래와 같습니다
yoon0037@flinders.edu.au

조사 참여 후기는 어떻게 알 수 있나요?

연구조사 마감 후, 연구 결과에 대한 내용은 모든 조사 참여자 분들에게 이메일 또는 우편으로 보내드릴 것입니다. 연구 조사 관련 정보 내용을 읽어 주셔서 감사합니다. 조사 참여에 관한 초대에 응해 주실 것을

2

바랍니다.

3

Appendix 7 Consent forms for Australian participants

PARTICIPANT PHOTOGRAPH RELEASE FORM

"Selling the artwork, not the label"

I ....

agree to the photographs and images of artworks that are created by an artist with cognitive impairment including ASD, intellectual and cognitive disabilities on behalf of the artist. I have taken for the *research study "Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment"* (as requested in the Participant Information Sheet) to be used for: [please circle whichever applies]

researcher's background analysis only / not for display	agree/don't agree

1.   I have read the information provided in the Participant Information Sheet.

2.   Details of procedures and any risks have been explained to my satisfaction.

3.   I am aware that I should retain a copy of the Information Sheet and Participant Photograph Release Form for future reference.

4.   I understand that:

- Photographs will be numbered not labelled to maintain anonymity.

- However, due to the small population of artists with cognitive impairment, I am aware of that complete anonymity may not be possible.

Co-signature of Participant artist... **Date**..................

Signature of Participant (caregiver/art staff) .... **Date**..................

I certify that I have explained how photographs will be used to the volunteer and consider that she understands what is involved and freely consents to participation.

Researcher's name...

Researcher's signature...   **Date**.........................

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CONSENT FORM FOR PARTICIPATION IN RESEARCH (interview)

> "Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment.

I ....

being over the age of 18 years hereby consent to participate as requested in the Information Sheet for the research project with the title listed above.

1. I have had the opportunity to discuss taking part in this research with the artist with cognitive impairment who is happy to be involved in this research.

2. I have read the information provided.

3. Details of procedures and any risks have been explained to my satisfaction.

4. I agree to audio recording of my information and participation.

5. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

6. I understand that:

    • I may not directly benefit from taking part in this research.

    • Participation is entirely voluntary, and I am free to withdraw from the project at any time; and can decline to answer particular questions.

    • The information gained in this study will be published as explained, and my participation will be strictly confidential. However, due to the small population of artists with cognitive impairment, I am aware of that complete anonymity may not be possible.

    • I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Co-signature of Participant artist.. Date...................

Signature of Participant (caregiver/art staff) .... Date.................

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name...

Researcher's signature... Date........................

Appendix 8 Consent forms for Korean participants
Photo Consent

사진 촬영 자료 사용 동의서

"Selling the artwork, not the label"
"장애란 꼬리표를 뗀, 작품 그 자체로 인정"

본인 ……………………………………………………………………………………………………는
발달장애 아티스트의 작품 사진 촬영 자료를 사용하는데 동의합니다. 참가자는 "장애란 꼬리표 뗀,
작품 그 자체로 인정". 발달장애를 가진 예술가들의 전문 예술가로서 대중의 인식을 향한 예술적
진보와 경험을 연구에 참여하고 있습니다. (사진 자료 사용 용도는 연구과제 정보지를 참고)

동의여부에 따라 선택해주세요.

사진자료는 출판 목적이 아닌, 연구자료 수집 분석 목적으로만 사용됨	동의함 / 동의안함

1. 본인은 연구 참가자를 위해 전달된 연구에 관한 정보를 읽었습니다.

2. 절차 및 우려에 관한 세부 사항이 잘 설명되었습니다.

3. 나중에 참조 할 수 있도록 사진 촬영 자료 사용 동의서 사본을 보관해야 한다는 사실을 알고
있습니다.

4. 다음과 같은 사항을 이해하고 있습니다.

   • 익명 성을 유지하기 위해 사진에는 번호로 표기합니다.

   • 그러나, 발달장애가 있는 아티스트의 수가 적기 때문에 완전한 익명 성이 불가능 할
   수도 있음을 알고 있습니다.

참가 아티스트의 공동 서명 ……………………………………………………………………………
Date……………………….

연구 참가자 서명 (가족 또는 보호자)……………………………………………………………….
Date……………………….

본인은 참가자 분들에 사진의 용도에 관해 설명했고, 참가자 분들이 이해하고 참여에 본인의
자유의지로 동의한다고 증명합니다.

Researcher's name………………………………………………….…………

Researcher's signature………………………………………………..

   Date…………………………….

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이 연구과제는 Flinders University Social and Behavioural Research Ethics Committee 플린더스 대학
사회성 및 행동 연구 윤리 위원회(Project number: 8168). 연구 과제 윤리 승인에 관한 자세한 정보를
원하시면 위원 집행부에 연락 주시기 바랍니다.

연락처 +61 8 8201 3116 팩스 +61 8 8201 2035 이메일 human.researchethics@flinders.edu.au

Consent form for participation in research

연구 참여 동의서

" 장애란 꼬리표 뗀, 작품 그 자체로 인정 " ,

발달장애를 가진 예술가들의 전문 예술가로서 대중의 인식을 향한 예술적 진보와 경험을 연구

본인 …..은 18세 이상으로 연구 과제 정보에 따라 연구에 참여하여, 다음과 같은 사항에 동의 합니다.

1. 연구 과제와 참여에 관하여 발달장애를 가진 아티스트분과 상의하였고, 아티스트 분 또한 기쁘게 연구에 참여에 동의하십니다.

2. 전달된 연구 과제 정보를 읽었습니다.

3. 절차 및 우려에 관한 세부 사항이 잘 설명되었습니다.

4. 개인 정보 및 참여에 관하여 오디오 녹음을 동의합니다.

5. 나중에 참조 할 수 있도록 연구 정보와 연구 참여 동의서 사본을 보관해야 한다는 사실을 알고 있습니다.

6. 다음과 같은 사항의 이해 합니다

    - 연구 참여함으로 나에겐 직접적인 이익은 없습니다.
    - 연구 참여는 전적으로 자발적이여야 하고, 나는 언제든지 질문에 답변을 거부 하거나 연구 참여를 중단 또는 철회 할 수 있습니다.
    - 연구 참여를 통해 얻어진 정보들은 출판 될 것이며, 개인 정보와 참여는 철저하게 기밀로 유지 될 것 입니다. 그러나, 발달장애가 있는 아티스트의 수가 적기 때문에 완전한 익명 성이 불가능 할 수도 있음을 알고 있습니다.
    - 나는 언제든지 녹음을 중단 할 수 있으며, 어떠한 불리함 없이 연구 참여를 철회 할 수 있습니다.

연구 참여 아티스트 공동 서명……………………………………………,……………………………… Date……………………,

인터뷰 참여자 서명 (가족 또는 보호자)……………………………………,……………………………, Date……………………,

본인은 참가자 분들에 사진의 용도에 관해 설명했고, 참가자 분들이 이해하고 참여에 본인의 자유의지로 동의한다고 증명합니다.

Researcher' s name……………………………………,…………………………….................

Researcher' s signature…………………………………………... Date…………………….

Appendix 9 Interview questions

Interview questions for family/primary carers of artists with cognitive impairment including ASD, intellectual or cognitive disabilities (during the interview, indicating the artist with cognitive impairment as 'the artist')

1. **About the artist and individual challenges**
   a) Tell me about the artist
      i) What's your relationship to the artist?
      ii) Does the artist have complex communication needs? (If yes, what's your main communication tool or approach?)
      iii) What can you tell me about their art and what kind of art they participate in?
      iv) How many hours per week does the artist spend per week on their artistic activities and engagement?
      v) When and how did you find out (her/his) interests/passion in creative arts (painting/crafts/animation/drawing etc)?
   b) What changes or impacts have you observed or has the artists expressed or experienced since becoming involved in art activities? Prompts if needed around
      i) Emotional changes, experiences or impact
      ii) Cognitive changes, experiences or impact
      iii) Behaviour changes, experiences or impact
      iv) Changes, experiences or impact to social interaction or social skills
      v) Changes, experiences or impact to communication skills

2. **Enablers**
   a) Do you plan or intend to encourage the artist to develop their skills and capacity so as to be recognised as a professional artist by the mainstream art community?
   b) Do you see their engagement with art activities as a leisure, a professional/ vocational pursuit?
   c) If the artist has been involved in art beyond just making work, do you think that he/she has achieved or experienced any publicly recognised as a professional artist?
   d) What are the enablers for maintaining the art engagement and/or improving his/her artistic capabilities?
   e) Have you found any mentors or art specialists or experts that have contributed to the artist's engagement in art activities? If so what have the contributed to and how and if not do you see the value in mentoring or specialist skill/capacity building.

3. **Barriers and limitations**

a) Have you found any challenges/barriers for maintaining the art engagement and/or improving his/her artistic capabilities?

b) Has the artist earned any income by selling (his/her) artworks or participating in a commercial artwork (including collaborative works)?

c) Has there been consideration or who has the responsibility for financial management of any income or for determining pricing, commissions and agency fees or management of intellectual property? If so what has been the experience? If not how does the management of these elements make you feel?

d) Is there any negative or positive impact on his/her government funding or supported income if he/she makes any additional income?

e) Have you or has the artist signed to any form of legal agreement regarding of (his/her) artwork/copyright/licensing (means using his/her artworks for commercial purposes)?

f) Do you help the artist with any decision-making?

4. **Expectation**

a) What meaning, or value does the family or significant others place on his/her involvement or engagement in the broader art community? Is recognition, access and inclusion an important end goal?

b) What's your expectation on the art community, art establishment or society in terms of supporting access and inclusion of artists with a disability?

Interview questions for art directors/staff/professional artists involved as a mentor within the art community (particular art communities for ASD, intellectual or mental disabilities)

1. **Individual experience**

a) How did you get involved in this art community? (additionally, explain your role/position and how long you've been working in the community)

b) What did you find the most **meaningful** things happened while you are working in the art community?

c) What did you find the most **challenging** things happened while you are working in the art community?

d) Have you noticed any improvement of the artist in terms of emotion, cognitive development, behavioural challenges, social interaction and communication?

e) Do you have a good understanding of individual physical and mental conditions for the artist to work with effectively?

f) Do you access any training or education to gain your knowledge of disability? If yes, please explain how you access the service including cost of learning and any institution involved.

g) Do you also have regular opportunities to improve and maintain your professional skills and career as an artist? If yes, how often you do and whether it helps to work with the artist as well? / if no, do you think it's needed?

2. **Enablers**
   a) Please explain general daily routine of the artist within the studio
   b) How much does the artist involved in the process of art projects, exhibitions and collaborative projects etc.?
   c) What's the title of calling the artist within the art community? And is there any reason of using the title and its benefits?
   d) Does the artist have an individual mentor? Or any professional support? What other supports do they need to maintain their activities?
   e) How do you explain the differences between professional artists and amateur in the art community? Is this different to mainstream art communities for non-disabled?
   f) Do you or Does the community have any specific strategies or frameworks to be practically implemented in the development of artistic skills and art careers for the artist?
   g) Do you have any comments regarding of supporting the artist in terms of their skills and art careers?

3. **Challenges**
   a) Do you think that the artist is publicly recognised as a professional artist? If not, do you think that they should be? Explain why.
   b) Is there any limitation of the artist to be recognised as a professional artist compared to an independent artist who is not living with a disability? What are the limitations?
   c) Have you found any distinctions between the artist and an independent artist with non-disabled in terms of artistic capabilities? Please, explain what they are.
   d) Have you experienced any behaviour/emotional or psychological challenges of the artist to deal with?
   e) What support can you access if you feel difficult to manage the particular situation of the artist's behavioural or emotional issues by yourself?

4. **Barriers and Expectations (applicable to art directors and CEO)**
   a) Service and management
      i) What is a model of your community? (non-profit organisation/social enterprise/for-profit company/private or government organisation)
      ii) What's the aim and goals of the community?
      iii) Do you have any specific frameworks or strategies to reach the goals?

iv) How you do maintain the financial supports for the community? Please, explain the income source (government funding/donations/ making products and selling goods/others)

v) Do you produce any goods or products by using artworks of the artists belong to this community or studio? If yes, how do you produce them? (using own investment/grants/third party involvement-e.g. licensing)

vi) Do you have any legal agreement between the artist and this community or studio in terms of using their artworks for any public or commercial uses?

vii) What opportunities have you offered to the artist to be a part of the mainstream art establishment? Successful or unsuccessful? Please, explain your journey.

viii) What's the relationship between the community and the artist? (service provider & clients/educational provider & learners/co-partnership as a collaborative project/art studio & artists accessing the studio) depending on the relationship, the entitlement of copyright for the artwork of the artists is variable)

b) Expectation and improvement
   i) Do you receive any legal advice or services? If yes, what areas? If no, do you wish to access?

   ii) Have you attempt to commercialise artworks of the artist? If yes, please explain your process and journey? Successful or unsuccessful? Benefits? Impact? Barriers? If no, why not? Do you wish to try?

   iii) How do you support the artists to develop their artistic capabilities and art careers to be recognised as a professional artist in the mainstream art establishment?

   iv) What are the challenges to manage and maintain the art community?

   v) What social and government supports should be improved to empower the artists?

   vi) What's your future plan and any additional comments?

Appendix 10 Approval notice

APPROVAL NOTICE

Project No.: **8168**

Project Title: "Selling the artwork, not the label"; exploring artistic progress and experience towards the public recognition as a professional artist for artists with cognitive impairment in the mainstream art establishment

Principal Researcher: Ms Jung Yoon

Email: yoon0037@flinders.edu.au

Approval Date: 20 December 2018 | Ethics Approval Expiry Date: **30 June 2020**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
   Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

   - all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

   - the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

   - the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

   This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. **Annual Progress / Final Reports**
   In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (2007-Updated 2018)* an annual progress report must be submitted each year on the **20 December** (approval anniversary date) for the duration

of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request <u>and</u> an annual report.

<u>Student Projects</u>
The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **20 December 2019** or on completion of the project, whichever is the earliest.

3. **Modifications to Project**
   Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

   - change of project title;
   - change to research team (e.g., additions, removals, principal researcher or supervisor change);
   - changes to research objectives;
   - changes to research protocol;
   - changes to participant recruitment methods;
   - changes / additions to source(s) of participants;
   - changes of procedures used to seek informed consent;
   - changes to reimbursements provided to participants;
   - changes / additions to information and/or documentation to be provided to potential participants;
   - changes to research tools (e.g., questionnaire, interview questions, focus group questions);
   - extensions of time.

   To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted <u>prior</u> to the Ethics Approval Expiry Date listed on this notice.

   <u>Change of Contact Details</u>
   Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. **Adverse Events and/or Complaints**
   Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

   - any complaints regarding the research are received;
   - a serious or unexpected adverse event occurs that effects participants;

- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Wendy Green

On behalf of Andrea Mather

Ms Andrea Mather (formerly Fiegert) **and Ms Rae Tyler**
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather	Monday - Friday	T: +61 8201-3116	E: human.researchethics@flinders.edu.au
Ms Rae Tyler	Monday, Wednesday and Friday mornings	T: +61 8201-7938	E: human.researchethics@flinders.edu.au
A/Prof David Hunter	SBREC Chairperson	T: +61 7221-8477	E: david.hunter@flinders.edu.au
Dr Deb Agnew	SBREC Deputy Chairperson	T: +61 8201-3456 E: deb.agnew@flinders.edu.au
SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

Research Development and Support |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

Appendix 11 Project brochures: Australian, Korean

Research Project for Exploring Artistic Progress and experience towards the Public Recognition as a Professional Artist for Artists with Cognitive Impairment

What is the project about?

This research project is about exploring artistic progress and individual experience towards the public recognition as a professional artist for artists with cognitive impairment including Autism Spectrum Disorder (ASD), intellectual and cognitive disabilities in the mainstream art establishment.

Information will be collected by interviews with family/carers of artists with cognitive impairment and their art supporters including art directors, staff, professional artists as a mentor, and volunteers in the selected art communities for ASD, intellectual disabilities and other disabilities. The interview is voluntary.

Why do you want to do this project?

We want to build effective strategies and pathways for art careers development of artists with cognitive impairment who want to be recognised as a professional artist.

This project is a part of a bigger project about Building a Culture of Social Collaboration for Emerging Artists with Cognitive Impairment in Art and Design Industries.

Who are we looking for?

We are looking for family/carers of artists with cognitive impairment including ASD, intellectual and cognitive disabilities who have been participating in the art communities for more than three years, and their art supporters in the art communities including art directors, staff, volunteers and professional artists as a mentor.

What will I be asked to do?

You are invited to participate in a one-on-one interview with a researcher. During the interview for family/carers of artists with cognitive impairment, the researcher will ask their perspective and experience with artists with cognitive impairment and their artistic progress. As their personal supporters and carers, they could be a witness for artists with cognitive impairment in terms of any changes and challenges that the artists with cognitive impairment have had since they started creative activities more seriously.

During the interview for art supporters, the researcher will ask their experience as an art supporter with artists with cognitive impairment. The questions have three parts including personal experience, strategies of working with artists with cognitive impairment, and administration and management of the art community.

Your experience will also help us make resources for building effective strategies of art careers development for artists with cognitive impairment.

Will any bad things happen to me if I am part of this project?

Time commitment: Participating in this research will require some of your time between 90-120 minutes.

Transport: If you agree to be interviewed, we will arrange for a researcher to come to you to interview you at your convenient.

Sensitive Issues: We do not plan to talk about sensitive topics relating to you personally or anything comfortable to you. But it is possible that you might feel upset or if anything we talk about is inappropriate to you, you can contact Lifeline on + 61 13 11 14 for support or counselling service. You can also talk to people you already know and trust, like a family member, friend or a social worker.

If you have any concerns about what could be negative about the study, please contact a researcher about it.

Will there be any good things for me if I participate in this project?

You will help the researchers and studies for artists with cognitive impairment to develop art careers as a professional artist by sharing your experience and opinions.

Your experiences and perspective will be valuable information for understanding the current systems of art communities for individuals with cognitive impairment including ASD, intellectual and cognitive disabilities.

Your experiences and perspective will also help us to outline what needs to be improved and to analyse difference of art activities in art community for disability compared to art community for non-disability.

What if I don't want to be in this project?

You don't have to be in this project if you don't want to. You can stop being in this project at any time if you don't want to be continued.

What will happen to information about me?

If you give us any personal information, such as your name or date of birth, we will keep this information safe and confidential.

We will not keep your information with the provided information regarding of the interview questions. We will not give your personal information to anyone else or use it for anything else. However, due to the small population of potential participants, you may not be completely anonymous even though no identifying information will be published.

How can I be involved?

If you would like to be involved in an interview, you can send us an email or call us on the telephone to tell us. We can arrange a time and a place at your convenient for the one-on-one interview with you.

What if I have questions about the research?

If you have any questions about the research you can talk to one of the researchers, or send them an email.

Jung Yoon
email yoon0037@flinders.edu.au
Caroline Ellison
email caroline.ellison@flinders.edu.au
Peggy Essl
email peggy.essl@flinders.edu.au

Who is doing the research?

The researching team are people from Flinders University; Jung Yoon, Associate Professor Caroline Ellison & Ms Peggy Essl

Ethics Committee

A special group has looked at the way this project will be done and approved it (Project number: 8168). The group is the Flinders University Social Behavioural Research Ethics Committee.

The Committee wants to make sure that everyone's rights will be protected.

If you are worried about how your rights are being protected, you can contact:
The Executive Officer at Flinders University
Phone: 08 8201 3116
Fax: 08 8201 2035
Email: human.researchethics@flinders.edu.au

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연구 조사에 관한 정보 책자

"장애란 꼬리표 떼, 작품 그 자체로 인정"

발달장애를 가진 예술가들의 전문 예술가로서 대중의 인식을 향한 예술적 진보와 정형을 연구

College of Nursing and Health Sciences Research by Jung Yoon, Associate Prof. Caroline Ellison & Ms Peggy Essl

Flinders UNIVERSITY

발달장애를 가진 예술가들의 전문 예술가로서 대중의 인식을 향한 예술적 진보와 경험을 연구 프로젝트

어떤 연구 조사 인가요?

이 연구조사는 발달장애를 가지고 계신 예술 작가님들이 전문 예술가로서 활동하는 동안 경험했던 어려움 또는 성공적인 요인들에 대해서 탐구하는 것에 목적을 두고 있습니다.

발달장애 예술작가님들을 보호하시는 보호자 본인 또는 가족 그리고 예술적 지원을 하시는 담당자 분들과 함께 작업을 하시는 예술인 분들과의 인터뷰를 통해서 자료를 수집할 것 입니다. 인터뷰는 자발적인 참여 입니다.

왜 이번 연구 조사가 중요한가요?

이번 연구 조사는 발달장애 예술 작가들을 위해 좀 더 효율적인 환경과 사회적 지원을 발전해 나갈 수 있는 정책을 만들고자하는 큰 프로젝트의 한 부분으로써 현황을 조사하고 분석하는 중요한 연구 과정입니다.

누가 참여 할 수 있나요?

이번 연구 조사는 발달장애 예술작가님은 3년이 상 전문 예술작가로서 작적을 두고 꾸준한 활동을 하시고 계시고 다른 예술가 분들과 달라 보 작품 또는 전시회에 참여하신 경력이 있으신 분들을 찾고 있습니다. 발달장애 예술작가님의 보호자 또는 가족 그리고 그 작가님의 예술적 활동 지원을 도와주시는 예술센터 관계자들의 인터 부 참여를 통해서 작가님들의 활동 상황과 환경에 대해 정보를 수집 하려 합니다.

어떤 질문을 받게 되나요?

인터뷰는 일대일로 조사원과 함께 진행됩니다. 인터뷰는 예술 단체 또는 개인차로 지원 중이 신 발달 장애 예술 작가님 께서 어떠한 과정과 지 원을 통해서 예술 활동을 지속 가능하게 하는 것 인지에 관한 예술 지원 팀 또는 작가님의 견해에 관해 질문을 할 것입니다.

발달장애에 예술 작가님들을 위해 개인적 또는 단 체적인 지원에는 어떤 것이 있는지 여 관련하여 어떠 한 환경과 어려움들이 있는지 여 견해서 크게 세 가지 부분으로 나누어서 질문을 할 것입니다. 세

가지 부분 예술 활동을 유지하기위한 개인적 어 려움, 성공요인 그리고 사회적 또는 개인적인 장 벽을 포함하고 있습니다. 인터뷰 질문지에 상세 히 나와 있습니다.

조사 참여자 분들의 소중한 경험과 견해는 실질 적인 정보 또는 현황을 알려줌으로 앞으로 어떠 한 사회적 지원과 개발이 발달 장애 예술 작가님 든을 위한 구체적 방책 마련에 도움을 주실 수 있 습니다.

조사에 참여 함으로 어떠한 불이익이 생길 수 있나요?

참여 시간: 조사 참여는 전체으로 자율적 입니다. 인터뷰는 90-120분 소요를 예상합니다. 만약 인터뷰 시간이 부족할 경우 조사원과 조사 참여자 분과 함께 상의하여 시간 연장을 결정할 것입니다.

장소: 참여자 분의 편의를 고려해, 조사원과 상의하신 후에 지정하시는 장소로 조사원이 직접 이동할 것 입니다.

민감한 논점: 조사원은 개인적으로 민감한 질문이나 인터뷰 참여자가 불편하게 느낄 질문이나 논점에 대해서는 예 기하지 않을 것을 원칙으로 두고 있습니다. 하지만, 부득이하게 민감한 질문이나 대화가 생길 경우 모든 있을 수 있음을 알려 드립니다. 참여자 분께서 불편함을 느끼실 경우 인 제든지 상담 지원 센터에 연락을 하실 수도 있고, 조사원에 게 알려주실 수 있습니다. 무료 상담을 서울 심리지원 센터 에 신청 하실 수 있습니다. 상담 전화번호는 02-2144-1192-5 입니다. 온라인 신청 주소는 아래와 같습니다.

http://www.psy-supporter.or.kr/online_new/inquiry.asp

조사에 참여 함으로 어떠한 이익이 생길 수 있나요?

조사 참여를 통해 나누어 주신 참여자 분의 값진 경험 은 이번 연구자들이 발달장애인분들의 예술적 참여 또 는 발달 장애인 예술 자기념들의 예술 활동을 더 나은 환경과 지원에서 지속해 나아 갈 수 있는 연구자원을 만들어 나아가는데 상당한 기여를 하실 수 있습니다.

참여자 분들의 소중한 견해는 지금 현재 발달장애 예술 가들이 겪고 있는 어려움이나 또는 현재 사회적 구조에 대한 이해도를 높이는데 도움을 주실 것 입니다.

그 뿐만 아니라, 나누어주신 정보와 견해를 통해서 좀 더 실질적이고 구체적인 방식을 연구하고 비장애인 예 술 단체와의 협력을 촉구하는 방법을 연구하는데 또한 기여 할 수 있습니다.

조사에 참여를 원하지 않을 경우에는 어떻게 하나요?

조사 참여는 전적으로 자발적으로 이루어져야 합니다. 혹시, 참여 도중 불편함이 있거나 우려가 있으셔서 참여를 원하지 않는다면 어느 때나 중단 할 수 있습니다.

조사 참여 중 개인적 정보 또는 신원 보호는 되나요?

조사 참여 중 성함 또는 어떠한 개인 정보는 요구하지 않을 것입니다. 부득이 하게 담당 조사원이 개인 정보를 알게 될 경우에도, 참여자 분에 관한 신원 확인이 가능한 정보는 숙기록에서 모두 제외 될 것입니다. 다만, 어떠한 개인 신원 정보를 논문에 기재 하지 않음에도 불구하고, 활동 중인 발달 장애인 예술 작가분들의 수가 많이 않음으로, 참여자 분의 신원이 완벽하게 미상이 되지 않을 수도 있음 을 알려 드립니다. 모든 참가자 분들의 정보와 결과를 돕은 안전하게 연구자들에 의해 보 호 될 것 입니다.

조사 참여는 어떻게 하나요?

조사에 참여를 원하신다면 담당 조사원에게 참여 동의 서 작성 후 서명을 하셔서 이메일로 담당 연구 조사원 에게 보내주시면 됩니다. yoon0037@flinders.edu.au 인터뷰 날짜와 장소는 개개인으로 상의 후 정할 수 있습니다.

조사 참여 중 질문이나 문의 사항이 생기면 어떻게 하나요?

조사 참여에 관한 질문이나 문의 사항이 있으실 경우, 아래에 나와 있는 조사원에게 이메일로 연락을 주시길 바랍니다.

Jung Yoon (담당 조사원: 윤정형)
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연구 조사원 들은 누구인가요?

플린더스 대학교 연구팀: Jung Yoon (윤정형: 담당 조사 연구원), Associate Professor Caroline Ellison (지도교수 연구원) & Ms Peggy Essl (조교 연구원)

윤리 위원회

이 연구조사는 윤리 위원회의 검증을 통해 실시되며 앞으로도 윤리 위원회의 감사하에 진행 됩니다. (Project number: 8168) 윤리 위원회는 플린더스 대학교 사회 행동 연구 윤리 위원회 입니다 (Flinders University Social Behavioural Research Ethics Committee)

해당 윤리 위원회는 모든 사람들의 인권 보호를 준수합니다.

인권보호에 관하여 우려가 있다면, 아래의 연락처로 문의 바랍니다.

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