Disability Identity Development in People with Congenital Blindness: An Evaluative Analysis of Gill's Model

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ABSTRACT

DISABILITY IDENTITY DEVELOPMENT IN PEOPLE WITH CONGENITAL BLINDNESS: AN EVALUATIVE ANALYSIS OF GILL’S MODEL

Lisa Gagliano, PhD
School of Interdisciplinary Health Professions
Northern Illinois University, 2021
Bryan Dallas and Greg Long, Co-Directors

This narrative research study used the Life Story Interview, within a participatory action framework, to explore how various psychosocial factors and experiences have impacted the disability identity development of people who are blind. The study sample consisted of eight individuals (ages 23-61) who self-identified as people with congenital blindness. Participants were recruited using selective sampling and snowball sampling techniques in collaboration with members of the National Federation of the Blind and others in the disability community. In-depth interviews were conducted with participants in accordance with methodological standards of the Life Story Interview to collect data in the form of the self-narrated life story. Thematic analysis techniques were used to identify themes of disability identity, with an emphasis on identity development within the context of interpersonal and societal interactions. Data were further analyzed to test for the alignment of themes generated from the narratives with thematic components of Gill’s first type of disability integration. Results from the analysis supported Gill’s model as a solid and applicable framework through which to explore the disability identity development of people who are blind. Findings from this study also contribute important data to the growing body of literature on disability identity development.
Keywords: disability identity, disability identity development, disability integration,

Gill’s model, blindness
ACKNOWLEDGEMENTS

In deepest gratitude to the participants of this study who so openly and honestly shared their life stories. It was a privilege and an honor to be present with each of them as they told of their unique journey of becoming. May their stories – and the stories of all people with disabilities – light the way to access, inclusion, and empowerment.

I also want to express my overwhelming gratitude to my dissertation committee: Bryan Dallas, Ph.D., Greg Long, Ph.D., and Amanda McCarthy, Ed.D. Through their generous sharing of time, expertise, and support, this project was brought to life. I remain committed to using all I have learned from them, and alongside them, to advance the status of people with disabilities and work toward achieving our shared goals of equality, collective empowerment, and social justice.

And, lastly, I want to express heartfelt gratitude to all those who have loved and embraced me on my own journey of becoming. In a most special way, to my family and “true blue” friends who I trusted with my hopes, insecurities, and ramblings along the path toward my doctoral degree. You light my way.
DEDICATION

To the professor who introduced me to the social model of disability:

Because of you, I am here –
Stretched out in the wholeness of my disabled body,

doing the work that sets me free.
TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>xi</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xii</td>
</tr>
<tr>
<td>LIST OF APPENDICES</td>
<td>xiii</td>
</tr>
</tbody>
</table>

### Chapter 1. INTRODUCTION: DISABILITY IDENTITY INTEGRATION AND DEVELOPMENT |

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overview of Disability Identity Development</td>
<td>1</td>
</tr>
<tr>
<td>Introduction to Disability Identity Development Research</td>
<td>2</td>
</tr>
<tr>
<td>Overview of Models of Disability Identity Development</td>
<td>6</td>
</tr>
<tr>
<td>Gill’s Model of Disability Identity Integration and Development</td>
<td>7</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>10</td>
</tr>
<tr>
<td>Disability Identity Development and Blindness</td>
<td>12</td>
</tr>
<tr>
<td>Research Question</td>
<td>13</td>
</tr>
<tr>
<td>Empirical Value of the Study</td>
<td>14</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>14</td>
</tr>
</tbody>
</table>

### Chapter 2. LITERATURE REVIEW |

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organizational Overview of Contents</td>
<td>17</td>
</tr>
<tr>
<td>Introduction to Identity Development</td>
<td>18</td>
</tr>
<tr>
<td>Identity Development</td>
<td>18</td>
</tr>
<tr>
<td>Chapter</td>
<td>Page</td>
</tr>
<tr>
<td>---------</td>
<td>------</td>
</tr>
<tr>
<td>Identity Development Theory</td>
<td>20</td>
</tr>
<tr>
<td>Seminal Theorists</td>
<td>21</td>
</tr>
<tr>
<td>Freud</td>
<td>21</td>
</tr>
<tr>
<td>Erikson</td>
<td>22</td>
</tr>
<tr>
<td>Mahler</td>
<td>25</td>
</tr>
<tr>
<td>Marcia</td>
<td>26</td>
</tr>
<tr>
<td>Bronfenbrenner</td>
<td>27</td>
</tr>
<tr>
<td>Disability and Postmodern Identity Theories</td>
<td>28</td>
</tr>
<tr>
<td>The Influence of Social Identity Theory on Identity Development</td>
<td>29</td>
</tr>
<tr>
<td>Minority Models of Identity Development Research</td>
<td>32</td>
</tr>
<tr>
<td>Foundational Models of Minority Identity Development</td>
<td>35</td>
</tr>
<tr>
<td>Cross</td>
<td>35</td>
</tr>
<tr>
<td>Sue and Sue</td>
<td>36</td>
</tr>
<tr>
<td>D’Augelli</td>
<td>38</td>
</tr>
<tr>
<td>Contemporary Models of Disability Identity Development</td>
<td>39</td>
</tr>
<tr>
<td>Introduction to Disability Identity Theory</td>
<td>39</td>
</tr>
<tr>
<td>Emerging Models of Disability Identity Development</td>
<td>44</td>
</tr>
<tr>
<td>Early Models of Disability Identity Development</td>
<td>44</td>
</tr>
<tr>
<td>Contemporary Models of Disability Identity Development</td>
<td>46</td>
</tr>
<tr>
<td>Stage Models</td>
<td>46</td>
</tr>
<tr>
<td>Gill</td>
<td>46</td>
</tr>
</tbody>
</table>
Chapter                                     Page
Gibson................................................................. 48
Domain and Status Models ....................................... 49
Putnam ................................................................. 49
Forber-Pratt and Zape ............................................... 50
Thematic Models ..................................................... 51
Caldwell ............................................................... 51
Dunn and Burcaw .................................................... 53
Empirical Investigation of Gill’s Model.......................... 54
Disability Identity Research of People Who Are Blind........... 56
Summary of the Importance of the Study........................... 58
3. METHODOLOGY ......................................................... 60
Study Design.................................................................. 60
Qualitative Research in Disability Identity Development ........ 61
Narrative Research....................................................... 62
Life Story Interview ................................................... 63
Life Story Interview and the Present Study ......................... 64
Procedures................................................................. 65
Sample Development................................................... 65
Sample Size.................................................................. 66
Data Saturation.......................................................... 67
Sampling Techniques.................................................... 68
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>69</td>
</tr>
<tr>
<td>Sample Selection</td>
<td>70</td>
</tr>
<tr>
<td>Participant Characteristics</td>
<td>71</td>
</tr>
<tr>
<td>Data Collection</td>
<td>73</td>
</tr>
<tr>
<td>Interview Process</td>
<td>74</td>
</tr>
<tr>
<td>Accessibility</td>
<td>77</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>78</td>
</tr>
<tr>
<td>Data Management</td>
<td>80</td>
</tr>
<tr>
<td>Privacy Shields</td>
<td>81</td>
</tr>
<tr>
<td>Data Coding and Theme Development</td>
<td>81</td>
</tr>
<tr>
<td>Phase One</td>
<td>82</td>
</tr>
<tr>
<td>Phase Two</td>
<td>85</td>
</tr>
<tr>
<td>Analysis of Disability Identity</td>
<td>85</td>
</tr>
<tr>
<td>Researcher Considerations</td>
<td>87</td>
</tr>
<tr>
<td>4. RESULTS</td>
<td>89</td>
</tr>
<tr>
<td>Thematic Components of <em>coming to feel we belong</em></td>
<td>91</td>
</tr>
<tr>
<td>Confronting Difference</td>
<td>91</td>
</tr>
<tr>
<td>Internalizing a Sense of Separateness</td>
<td>92</td>
</tr>
<tr>
<td>Conceptualizing the Meaning of Blindness</td>
<td>96</td>
</tr>
<tr>
<td>Awakening to Self-Potential</td>
<td>98</td>
</tr>
<tr>
<td>Social Exclusion</td>
<td>101</td>
</tr>
<tr>
<td>Chapter</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Bullying and Mistreatment</td>
<td>103</td>
</tr>
<tr>
<td>Access Barriers to Inclusion</td>
<td>106</td>
</tr>
<tr>
<td>Challenges to Employment Integration</td>
<td>118</td>
</tr>
<tr>
<td>Positive Peer Support</td>
<td>121</td>
</tr>
<tr>
<td>Desiring Inclusion</td>
<td>125</td>
</tr>
<tr>
<td>Desiring to be Seen</td>
<td>126</td>
</tr>
<tr>
<td>Resisting Separateness</td>
<td>130</td>
</tr>
<tr>
<td>Asserting Rights</td>
<td>133</td>
</tr>
<tr>
<td>Effective Self-Advocacy</td>
<td>135</td>
</tr>
<tr>
<td>Collective Empowerment</td>
<td>142</td>
</tr>
<tr>
<td>Expecting Access</td>
<td>149</td>
</tr>
<tr>
<td>Results of Analysis of Disability Identity</td>
<td>157</td>
</tr>
<tr>
<td>Blindness as Natural</td>
<td>159</td>
</tr>
<tr>
<td>Blindness as Strength</td>
<td>162</td>
</tr>
<tr>
<td>Summary of Results of Thematic Analysis</td>
<td>166</td>
</tr>
<tr>
<td>Psychosocial Factors that Influenced Disability Identity</td>
<td>167</td>
</tr>
<tr>
<td>Family Response to Blindness</td>
<td>167</td>
</tr>
<tr>
<td>Societal Misperceptions of Blindness</td>
<td>169</td>
</tr>
<tr>
<td>Educational Support</td>
<td>171</td>
</tr>
<tr>
<td>Access Barriers</td>
<td>172</td>
</tr>
<tr>
<td>Blind Community</td>
<td>173</td>
</tr>
<tr>
<td>Chapter</td>
<td>Page</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Other Blindness-Related Factors</td>
<td>175</td>
</tr>
<tr>
<td>5. DISCUSSION</td>
<td>177</td>
</tr>
<tr>
<td>Interpretation of the Findings</td>
<td>178</td>
</tr>
<tr>
<td>Confronting Difference</td>
<td>180</td>
</tr>
<tr>
<td>The Influence of Family Response on Perceptions of Blindness</td>
<td>181</td>
</tr>
<tr>
<td>Social Exclusion</td>
<td>183</td>
</tr>
<tr>
<td>The Influence of Societal Misperceptions on Inclusion</td>
<td>183</td>
</tr>
<tr>
<td>The Blind Community as a Source and Facilitator of Identity Growth</td>
<td>186</td>
</tr>
<tr>
<td>Desiring Inclusion</td>
<td>187</td>
</tr>
<tr>
<td>Experiences of Invisibility in Society</td>
<td>188</td>
</tr>
<tr>
<td>Asserting Rights</td>
<td>190</td>
</tr>
<tr>
<td>The Role of Self-Advocacy in the Assertion of Rights</td>
<td>190</td>
</tr>
<tr>
<td>The Collective Empowerment of the Blind Community</td>
<td>192</td>
</tr>
<tr>
<td>Expecting Access</td>
<td>193</td>
</tr>
<tr>
<td>A Vision of Access that is Beyond Accessibility</td>
<td>194</td>
</tr>
<tr>
<td>Limitations of the Study</td>
<td>195</td>
</tr>
<tr>
<td>Validity and Reliability</td>
<td>197</td>
</tr>
<tr>
<td>Validity</td>
<td>198</td>
</tr>
<tr>
<td>Reliability</td>
<td>199</td>
</tr>
<tr>
<td>Considerations for Future Research</td>
<td>200</td>
</tr>
<tr>
<td>Conclusion</td>
<td>203</td>
</tr>
<tr>
<td>Chapter</td>
<td>Page</td>
</tr>
<tr>
<td>-----------------</td>
<td>------</td>
</tr>
<tr>
<td>REFERENCES</td>
<td>206</td>
</tr>
<tr>
<td>APPENDICES</td>
<td>219</td>
</tr>
</tbody>
</table>
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Thematic Analysis Flow Chart</td>
<td>79</td>
</tr>
<tr>
<td>2. Thematic Components of Gill’s (1997) First Type of Disability Integration <em>(coming to feel we belong)</em></td>
<td>86</td>
</tr>
<tr>
<td>3. Summary of Results from an Analysis of Confronting Difference</td>
<td>93</td>
</tr>
<tr>
<td>4. Summary of Results from an Analysis of Social Exclusion (Themes 1-3)</td>
<td>102</td>
</tr>
<tr>
<td>5. Summary of Results from an Analysis of Social Exclusion (Theme 4)</td>
<td>103</td>
</tr>
<tr>
<td>6. Summary of Results from an Analysis of Desiring Inclusion</td>
<td>127</td>
</tr>
<tr>
<td>7. Summary of Results from an Analysis of Asserting Rights</td>
<td>136</td>
</tr>
<tr>
<td>8. Summary of Results from an Analysis of Expecting Access</td>
<td>151</td>
</tr>
<tr>
<td>9. Summary of Results from an Analysis of Disability Identity</td>
<td>158</td>
</tr>
<tr>
<td>10. Alignment of Themes Contained in Life Story Narratives with Thematic Components</td>
<td>168</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Example of Phase One, Step 1</td>
<td>83</td>
</tr>
<tr>
<td>2. Example of Phase One, Step 2</td>
<td>84</td>
</tr>
</tbody>
</table>
# LIST OF APPENDICES

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. DATA COLLECTION PROCEDURE CHART</td>
<td>219</td>
</tr>
<tr>
<td>B. INTERVIEW GUIDE</td>
<td>222</td>
</tr>
<tr>
<td>C. THEMATIC ANALYSIS OF NARRATIVES</td>
<td>227</td>
</tr>
<tr>
<td>D. DISABILITY IDENTITY THEMES</td>
<td>229</td>
</tr>
<tr>
<td>E. WRITTEN ADVERTISEMENT ABOUT THE STUDY</td>
<td>231</td>
</tr>
<tr>
<td>F. INFORMED CONSENT FORM</td>
<td>233</td>
</tr>
</tbody>
</table>
CHAPTER 1
INTRODUCTION: DISABILITY IDENTITY INTEGRATION AND DEVELOPMENT

Overview of Disability Identity Development

Identity development, defined as the psychodynamic process by which individuals develop a sense of self within the context of socio-cultural norms and demands, is a key construct in human development and personality theories (Syed et al., 2011; Vignoles et al., 2011). It attempts to answer the fundamental questions *Who Am I? What makes me how I am? Who am I called to become?* Identity formation underlies healthy psychological development in that it aims to move individuals toward achieving an internalized sense of unity, utility, and personal life meaning (Erikson, 1963, 1968; Gill, 1997). Whereas a fractured or disjointed identity causes unresolved internal crises and psycho-emotional discordance, a well-formed identity leads to a coherent sense of self that supports a person’s ability to develop healthy attachments with others, the environment, and even their dreams (Bartholomew & Horowitz, 1991; Oyserman et al., 2012). Identity development, therefore, can be appreciated as a quest of the lifetime, across the lifespan, for all persons in their striving toward psychological wholeness.

People with disabilities are like all individuals in their need to develop a solid sense of self. Disability, whether hidden or visible, acquired or congenital, is a part of one’s being that must be negotiated into the concept of one’s self. Disability as a unique identity is an emerging area of empirical interest. Although disability is not a salient aspect of the self-concept of all people with disabilities (Murugami, 2009; Olkin, 1999), research on disability identity suggests
that it is an important component of the psychosocial health for many who live with disability (Bogart 2014, 2105; Darling, 2013, 2019; Dunn & Burcaw, 2013; Gill, 1997). An individual is said to possess an affirming disability identity when they have achieved a “positive sense of self and feeling of connection to, or solidarity with, the disability community” (Dunn & Burcaw, 2013). The process of developing a disability identity, however, is especially complex, as incorporating disability into the self-concept involves direct confrontation with beliefs, attitudes, and perceptions that largely frame disability as an undesirable characteristic best left minimized, disguised, abandoned, or discarded. People with disabilities, therefore, must grow into self-awareness amidst psychosocial factors and dynamics that influence separation of the disability from the self, and the self from the rest of society. The resolution of this polarizing tension is a primary task of the healthy identity development for people with disabilities (Gill, 1997). It requires integrating disability into the self on both intrapsychic and relational levels – a process by which individuals come into alignment with their disability within the context of the body, psyche, community, and society.

Introduction to Disability Identity Development Research

As noted, identity development has been extensively examined in the social and psychological sciences. Erikson (1963, 1968) laid the theoretical groundwork for identity development research with his stage model, and subsequent theorists have elaborated on the concept by examining identity formation from ethnic, multicultural, and minority group perspectives (Cross, 1978; D’Augelli, 1994; Sue & Sue, 2013). It has only been in recent decades that identity development has been empirically explored in disability populations (Forber-Pratt et al., 2017). The growing interest in disability as an identity correlates with an
increased understanding of disability as a complex social construct. Whereas dominant conceptions frame disability as a medical problem that exists within an individual, disability scholars and activists assert that disability is socially-determined – a condition that is a result of barriers, stigma, and prejudicial attitudes posed by the physical and social environments (Goering, 2015; Olkin & Pledger, 2003). From this social model perspective, it is emphasized that self-perceptions of disability are influenced by an individual’s own unique experience with disability as well as the meaning that society ascribes to the disability. Thus, a thorough exploration of disability identity development requires it to be conceptualized as a social process as much as a developmental one.

There is a small but growing body of literature on disability identity development in the rehabilitation research that identifies it as an important area of scholarly focus. It has been well-established that disability-related stereotypes, stigma, and oppressive practices devalue people with disabilities and reinforce their exclusion from society (Murray, 2002; Olkin, 1999). This long-standing climate of hostility toward individuals with disabilities has caused many people with disabilities to internalize societal beliefs about disability that have constrained their capabilities and legitimized negative views of disability-related characteristics. (Murugami, 2009; Shahnasarian, 2001). Examining disability identity requires consideration for these social factors and their impact on how people with disabilities come to see themselves.

The existing disability identity research has explored the factors that have influenced a person’s self-concept, interpersonal relationships, and their interactions with society. As a whole, research suggests that disability identity is largely impacted by a person’s beliefs about disability and their social environment (Darling, 2003; Dorozenko et al., 2015; Kinavey, 2006; Zhang & Haller, 2013). Ostrander (2008), for example, found that men from racial and ethnic minority
groups who had sustained violent, acquired spinal cord injuries struggled with integrating the injury into their social roles and sense of self. This was due to negative, societal messages about disability that were in direct conflict with participants’ sociocultural expectations of what it means to be a man. Indeed, stigma and a sense of shame associated with disability prevent many people from developing a positive disability identity (Onken & Slaten, 2000). This is illustrated in a study by Mogensen & Mason (2015) who examined disability identity in adolescents with Autism Spectrum Disorder. They found that the self-perceived meaning of an Autism label prevented participants from positively associating with their disability. Such studies support views of disability scholars, such as Shakespeare and Watson (2001) and Crow (2001), who argue that the social model disability resists and combats disability-related stigma, which in turn, may have a profound positive impact on the inclusion and identity development of people with disabilities.

The impact of a positive affirming disability identity on the psychological and social health of people with disabilities cannot be understated. Studies that have explored the impact of disability identity on the psychosocial health of people with disabilities have consistently yielded positive results. Findings suggest that an affirming disability identity is associated with psychological well-being (Bogart, 2014, 2015; Darling, 2013, 2019), self-esteem (Nario-Redmond et al., 2013), social integration (Cunnah, 2015; Dunn & Burcaw, 2013; Gill, 1997), sense of belonging (Raver et al., 2019), and self-perceived quality of life (Bogart, 2014; Clarke & Black, 2005; Siebers, 2017). These outcomes are vital to building the resilience that is needed for adaptive functioning and increasing levels of personal empowerment (Stuntzner & Hartley, 2014) Perhaps among the most revealing of findings are expressed through the narratives of people with disabilities themselves who express the transformative effects of having fully
embraced and integrated disability into their self-concept (Caldwell, 2011; Dunn & Burcaw, 2013; Gill, 1997). One illustrative example that is a powerful representation of this transformation is an excerpt provided by Gill (1997, p. 44). This autobiographical passage describes the experience of a student with a learning disability who through her involvement with the disability community was able to integrate disability into a positive sense of self:

I…began to look at my disability in a very different way. This change was catalyzed by experiences I started to have with other disabled students…I had finally found a group of people with whom I did not have to consistently play the role of the ‘happy overcomer’. I no longer regard disability as an inherently negative condition, but rather as one of the unique and positive characteristics that comprise our society as a whole. I can honestly say that I like myself, not despite, but because of my differences. And as I have come to value my disability as an integral part of who I am, others have too. (Reiling, 1993)

Studies to date on disability identity development are mostly exploratory in nature and limited both in quantity and scope. Theoretical models specific to disability identity formation have been developed, however none have been widely adopted or empirically tested (Forber-Pratt et al., 2017). Similarly, only a few disability identity measures exist and most have been adopted from other social sciences and not rigorously psychometrically assessed with disability populations. Further complicating the research is the high degree of variability and diversity inherent to disability that impact an individual’s experience with, and response to, disability. Many studies use cross-disability samples or samples with wide ranging or loosely defined disability characteristics (e.g., adults with psychiatric disabilities, individuals with unspecified mobility impairments). Few demonstrate evidence of strictly controlling for confounding factors (e.g., socioeconomic status) to allow meaningful conclusions to be drawn from the data. Moreover, identity development, as it is psychologically defined, is a developmental task that requires higher-level mental and cognitive functioning. Therefore, it is not a task that is relevant
to all types of disabilities or people with disabilities. As such, the meaning of data is less about generalizability and more about developing a deeper understanding of the phenomenon.

Overview of Models of Disability Identity Development

Several models of disability identity development have emerged in the rehabilitation research. Arthur Frank (1993), Kathy Charmaz (1994, 1995), and Carol Gill (1997) were among the first researchers to explore identity development in disability populations. To date, there are several models identified in the extant body of research, each of which theoretically describe identity development from varying perspectives. It is important to note that it has been difficult for researchers to develop an overarching model of disability identity development, as it is a highly individualized psycho-emotive process that is influenced by factors that are intrinsic and extrinsic to both the disability and the person with the disability. The existing models do, however, provide a useful framework through which disability identity development can be more deeply examined and theoretically explained.

The current models of disability identity development vary significantly from one another. One point of divergence is the foundational basis used in the construction of the models (e.g., social or medical model of disability), which consequently exposes identity development through unique philosophical lenses. The paradigmatic structure that attempts to explain how identity development unfolds also differs. Some models use a stage model (Gibson, 2006; Darling & Heckert, 2010), indicating a component of sequential progression to the identity formation process, whereas several others suggest that individuals move through specific phases or states that are neither time-dependent nor interdependent of one another (Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Putnam, 2005). Despite these difference, personal acceptance
and communal attachment with the disability community appear as the common threads that intertwine experiences of disability identity development across the models. The unifying power of personal acceptance and communal attachment in the formation of disability identity is clearly brought to light through the work of several researchers. Putnam (2005) and Caldwell (2011), for example, found that disability activists and leaders were found to possess affirming disability identities that were deeply rooted in the shared goals and vision of the disability community. Similarly, studies conducted by Gill (1997) and Forber-Pratt and Zape (2017) point to the significant, positive impact that peer-level interactions with others with disabilities have in guiding a person to embrace their disability. Gill defined the experience of finding a community of others with shared experiences of disability in her model as “coming home.” Indeed, it is this deep experience of homecoming that encapsulates the sense of belonging that is pivotal to developing a positive disability identity and a celebratory sense of self.

Gill’s Model of Disability Identity Integration and Development

Gill’s (1997) model of disability identity development is a prominent theory in the rehabilitation research. Gill’s model stands out in the literature as unique among all existing models for several reasons. First, Gill self-identifies as a person with a disability and someone with cultural ties to the disability community. Consequently, her model has been developed by way of an insider’s perspective with access to rich insights offered within the disability community. This personal experience enriches the identity research with perspective that wholly embraces the complexities of disability and maintains a sensitivity for the subtleties that form meanings around disability. Additionally, Gill strictly conceptualizes disability identity development within a social model framework. This orientation frames people with disabilities
as a minority group and identity formation as a socially mediated developmental process. As such, Gill’s model is structured to support a multidimensional exploration of disability identity development while aligning with concerns for empowering people with disabilities through deconstructing barriers to self-acceptance, positive group identity, and a celebration of disability. Furthermore, Gill’s model offers an expansive framework to explore the disability identity development of people with disabilities across the spectrum, including both congenital and acquired disabilities as well as disabilities that are both apparent and non-apparent. This theoretical feature of her model appreciates the diversity of the disability experience, as no two people, even those with the same disabilities, experience it in the same way.

One of the unique strengths of Gill’s (1997) model is that it was developed by way of an insider’s perspective to disability. Gill herself openly identifies as a person with a disability with cultural ties to the disability community. This insider’s perspective significantly increases a researcher’s physical, social, and cultural access to the marginalized group, which may, in turn, provide for a depth and breadth of insights to illuminate the data (Bonner & Tolhurst, 2002). Although this is empirically advantageous in many ways, there is also the potential for a negative impact on the research process. This may include a loss of objectivity, erroneous influence of interpretive bias, and conflicts caused by role duality (Unluer, 2012). This researcher contends that Gill not only effectively mitigated these factors but that she, in fact, needed this insider’s perspective to construct her model. Unlike other models of disability identity development, Gill’s model is firmly rooted in the voices and lived experiences of people with disabilities gathered over decades of work in her diverse roles as a psychologist, academic, researcher, and member of the disability community.
Gill (1997) posited four distinct types of disability integration that underlie the development of a sound disability identity: coming to feel we belong, coming together, coming home, and coming out. Each type of disability integration is categorically defined by dynamic individual-societal interactions that lead to a sense of unity and belonging on various personal and group levels. Successful movement through each type of integration represents development toward an ever-strengthened disability identity—one that supports higher levels of self-definition, interpersonal comfort, social integration, and authentic personal expression.

The four types of integration described in Gill’s (1997) model are characterized by intrapsychic (i.e., with oneself) and inter-social (i.e., with others) components. Coming to feel we belong is marked by the recognition that exclusion of people with disabilities is a result of restrictive environments and expectations rather than a result of impairment. This form of integration allows individuals to grow into awareness that they have a “right to inclusion in society” (Gill, 1997, p. 42). This right to inclusion in society may be behaviorally expressed through self-advocacy and other efforts to assert one’s access rights in the workplace and the community. Coming home describes the expansion of a person’s interactions to include others with disabilities. Through these interactions, people with disabilities are prompted to re-examine dominant conceptions of disability and explore the value of stepping away from the normative culture into one that embraces disability as wholeness. In this type of integration, individuals may gravitate toward others with disabilities and come to thoroughly enjoy the company of those who are bound together through the shared experience of disability.

The third type of disability integration that Gill (1997) defined is coming together. Coming together centers around achieving disability acceptance and coming to perceive disability not so much as a condition to be overcome, but rather as an aspect of a person that has
value in embracing. *Coming together* is a defining point in disability identity development when individuals develop an appreciation of their disability as a valid and valuable aspect of themselves. Such persons may no longer desire to hide or minimize their difference in order to fit in with able-bodied norms of society. Advancement to the last type of integration—*coming out*—illustrates crossing the threshold into a newfound sense of personal integrity and freedom in which there is congruence between how one views one’s self and how one presents in the community. With a strengthened self-concept and appreciation for one’s self that includes disability, individuals are able to engage in society with an increased capacity for relationships with others. This level of disability identity integration is exemplified in the person who is able to navigate an able-bodied world with confidence in their self-worth, value, and rightful place in society; and, with recognition of the unique aspects of themselves that both set them apart from others and unite them.

**Purpose of the Study**

Disability identity development has been identified as an important aspect of the psychosocial well-being of people with disabilities. Yet, despite its significance, there is a scarcity of research on the topic and few theories that attempt to explain how identities are formed around disability. This has limited theoretical advancements in disability identity research as well as limited the availability of an empirically based disability identity framework from which to improve outcomes for individuals with disabilities. These limitations are current barriers to the growth and implications of disability identity research. Targeted research efforts are needed to examine existing frameworks of disability identity development. Such findings will not only drive theoretical developments, but they will guide future disability identity
research that is needed to translate disability scholarship into culturally-competent rehabilitation practice.

Gill’s (1997) model of disability identity development has been a foundation of theoretical growth in disability identity research, representing one of the first and the most well-developed models in the extant body of literature. It has served as a pillar of theoretical growth in disability identity research. However, like other models of disability identity development, it lacks rigorous empirical testing. A thorough literature review revealed an absence of any former studies that have formally assessed Gill’s model. Therefore, it was important to limit the scope of this study by focusing on a single integration type. Although each type of disability integration is useful in describing distinct components of disability identity development, the first type—coming to feel we belong—serves as the underpinning of the model. Moreover, considering the impact of disability variability and sampling limitations noted in prior studies, it is important to examine theoretical components with a specific disability group. Thus, the purpose of this study was to conduct initial, exploratory steps to formally test Gill’s model by assessing for the alignment of theoretical components of the first integration type (i.e., coming to feel we belong) with the lived experiences of people who are blind.

A thorough examination of the first integration type will help illuminate the factors that impact how people come to form identities around disability in relation to how they perceive disability and its impact on their interactions with society. Gaining deeper insight into the formative process by which individuals grow into awareness that they not only can be contributing members of their communities, but in fact, should be is central to exploring the foundation of Gill’s model. Such knowledge, brought to light through the voices of individuals with disabilities, allows for a critical analysis of the model’s theoretical backbone and
contributes to the growing body of literature on disability identity development. It also aligns well with the aims of contemporary rehabilitation research to advance the status, psychosocial well-being, and empowerment of persons with disabilities.

Disability Identity Development and Blindness

Exploring components of Gill’s theory with people who are blind offers several unique advantages. To begin, vision disabilities are common. Approximately 285 million people globally (World Health Organization, Global Data on Visual Impairment, 2010) and over seven million people nationally (Erikson et al., 2020) live with vision loss. Despite this prevalence, there were only three studies that were identified in the researcher’s comprehensive review of the literature that examined disability identity with exclusively with people living with blindness or vision loss (Gibson et al., 2018; Pinquart & Pfeiffer, 2013; Zapata, 2018). The three studies that were identified were quantitative in design and, therefore, offered limited insight into disability identity as it relates to the lived experiences of people who are blind. This proposed qualitative study will be among the first to contribute the voices of individuals who are blind to the body of disability identity research.

A variety of characteristics associated with blindness align well with important components of Gill’s (1997) theory. To begin, group identity and connections with the disability community are central themes of her model. People who are blind are positioned well to encounter other individuals with vision loss or other disabilities as part of the specialized educational and vocational training services are typical of their rehabilitation process across the lifespan. These experiences provide opportunities to build connections with the blind and disability communities. Moreover, the blind community is a distinct and well-established
disability community that has been unified by the shared experience of vision loss and strengthened by a collective political push for equal access in society (Fleischer & Zames, 2011; Rembis et al., 2018). This emphasis on the value of maintaining cultural ties and connection with one’s disability community while supporting movement toward higher levels of societal inclusion is consistent with Gill’s perspective on integration.

Using this population offers another, more practical advantage. Specifically, the researcher has direct access, through colleagues and acquaintances who are blind, to the blind community. This supports access to a large pool of potential participants. The importance of sample development to the methodological quality of the study renders this a significant research advantage. Furthermore, a focus on the blind population rather than a disability population to which the researcher is a member provides ample separation from the subject. This supports neutrality in the data management process and minimizes the potential for the negative impact of reflexivity and interpretive bias (Mantzoukas, 2005). It will be important for the researcher to clarify her role and proactively address her shared experiences, both as an insider to disability and as an outsider to blindness, on the collection and analysis of data.

Research Question

This cross-sectional study used qualitative research methods, within a participatory action framework (Balcazar et al., 2006), to explore the disability identity development of individuals who are blind. The researcher conducted in-depth interviews with participants to collect data in the form of their self-narrated life story. Interviews were conducted in accordance with a Life Story Interview methodological approach (Atkinson, 1998) to elicit descriptively rich narratives that thoroughly addressed the following research question: How do the psychosocial factors and
factors related to the disability identity of people with congenital blindness align with the thematic components of Gill’s (1997) first type of disability integration (i.e., *coming to feel we belong*)?

Empirical Value of the Study

This research study was the first study that aimed to formally test a prominent model of disability identity development. As argued, these data have been needed to establish and advance the theoretical foundation and apply these findings to rehabilitation practice. More thoroughly understanding the identity formation of people with disabilities is an important step to identifying and addressing the factors that contribute to their psychological integrity and social wellness. Perspective and insights gained from identity development research have the capacity to expand our understanding of disability and introduce new ways to better serve and support those living with disability. These are essential data for rehabilitation professionals who work with people with disabilities, especially those who do not have disabilities themselves. It also provides an opportunity for the deep reflections and sharing of narratives among people with disabilities that may serve to guide people with disabilities back home to themselves and back home to each other.

Definition of Terms

*Disability:* According to the ADA, disability is (a) a physical or mental impairment that substantially limits one or more major life activities of such an individual, (b) a record of such an impairment, or (c) being regarded as having such an impairment (Americans with Disabilities Act, 42 U.S.C. § 12102).
Disability Community: Referred to as a broad group of people who are bound together by the shared experience of disability and common goals for disability justice and equality (Caldwell, 2011; Putnam, 2005).

Disability Identity: An identity that regards disability as a vital and valuable aspect of the self-concept and includes social or emotional connection to the disability community (Darling, 2013; Dunn & Burcaw, 2013; Gill, 1997)

Disability Identity Development: The psychosocial process by which a person forms an understanding of who they are as someone who has a disability and as part of the larger disability community (Forber-Pratt et al., 2017; Gibson, 2006; Gill, 1997)

Disability Integration: The psychological process by which a person with a disability incorporates their disability into their self-concept (Gill, 1997).

Disability Pride: A feeling of pleasure and dignity associated with having a disability. “An ideal-typical identity that has come to be associated with disability rights activists; its polar opposite is disability shame, a view based on stigma” (Darling, 2013, p. 7).

Identity: Refers to “conceptions of the self, expressions of individuality, and accounts of group affiliation” (Dunn & Burcaw, 2013, p. 148).

Identity Development: Conceptually defined as an intrapsychic process by which individuals come to form an understanding of who they are and to what or where they feel they belong (Erikson, 1968; Gill, 1997).

Inclusion: Describes the ability of individuals, regardless of disability or status, to access and participate in the community and be regarded as valuable members of the community.

Life Story Interview: A methodological approach to narrative research that aims to elicit a person’s life story in its most complete and authentic form. (Atkinson, 1998).
Participatory Action Research: A research framework that actively includes members of the community of interest in the design and implementation of research activities so that the research remains informed and guided by these individuals (Baum et al., 2006).

Psychosocial: The combined influence of psychological factors and the social environment on a person’s well-being and ability to function.

Self-Concept: Individuals’ views and beliefs about themselves. In the psychological sciences, this word is used interchangeably with the term identity (Baumeister, 1999).

Sense of Self: Used to refer to one’s intrapsychic understanding of themselves.

Social Model of Disability: An orientation to disability that views disability as a condition that results from systemic, organizational, environmental, and/or attitudinal barriers rather than the impairment itself (Shakespeare, 2010).
CHAPTER 2
LITERATURE REVIEW

Organizational Overview of Contents

This literature review will describe theorists and models foundational to disability identity development research. The discussion will begin with an overview of the major findings of identity development research in the social and psychological sciences. This will lead to a review of seminal theorists and models that have laid the foundation from which all identity research has grown. Next, the discussion will proceed to post-modern theories of identity development, including those that pertain to minority group populations. A review of each model will include an analysis of its applicability to people with disabilities to aid in contextualizing the empirical evolvement of identity development models to include disability populations. The discussion will then shift to a detailed and exclusive focus on the models of disability identity development that are contained in the rehabilitation literature. This will lay out the empirical landscape of disability identity research and point to the strengths and limitations of existing theoretical frameworks. The literature review will conclude with an argument for further investigation of Gill’s model of disability identity integration and development. It will underscore the importance of this study in advancing the psychosocial well-being of people with disabilities.
Introduction to Identity Development

Identity is a core construct of human development that is at the essence of self-definition, self-affirmation, and one’s connection to others. It is central to the unfolding quest of all persons to respond to the question *Who am I?* (Syed et al., 2011; Vignoles et al., 2011). Theoretical interest in identity development can be traced back to the early days of psychology and has resulted in voluminous research over several decades. What was first viewed as primarily a developmental task of adolescence (Erikson, 1968; Marcia, 1966) is now recognized by contemporary scholars as a dynamic, multidimensional process that extends across the lifespan (Cramer, 2004; Kroger, 2015; Grotevant & Cooper, 1998; Oyserman et al., 2012). Identity research has vastly expanded to include multicultural, minority, and other diverse populations (Cross, 1971; D’Augelli, 1994; Sue & Sue, 1990, 1991). As awareness of disability as a social construct continues to grow, so does the interest in exploring how factors and perspectives that influence experiences with disability impact the identity development of people with disabilities. This study will satisfy this burgeoning interest by furthering efforts to identify and establish a validated, theoretical framework through which researchers can explore how individuals form identities around disability.

Identity Development

Identity development is conceptually defined as an intrapsychic process by which individuals come to form an understanding of who they are and to what or where they feel they belong (Erikson, 1968; Gill, 1997). Identity is constructively complex, embedded in and expressed through personal characteristics, group identification, and social roles (Oyserman,
Identity, also referred to as personal identity in the psychological sciences, is best understood as the “distinctive combination of personality characteristics and social style by which one defines oneself and by which one is recognized by others” (Grotevant, 1998, p. 1119). Identity, by this definition, is quite isomorphic with self-concept, as both terms refer to an individual’s beliefs about who they are and their patterns of relating to others (Baumeister, 1999).

Identities can be formed around multiple aspects of an individual. Identities can be associated with a person’s intrinsic traits or individual characteristics, such as gender, race, ethnicity, disability, and/or sexual orientation. They can also be formed around extra-personal aspects, such as an individual’s culture, socioeconomic status, interests, social roles, group affiliations, and life experiences (Oyserman et al., 2012; Verkuyten, 2005). The body of literature on identity development supports the need to examine identity as a multifaceted phenomenon that is malleable and contextualized (Bosma & Kunnen, 2001; Kroger, 2015; Luyckx et al., 2006; Marcia, 2002). Findings suggest that most people claim multiple identities, overlapping identities, or assume distinct identities at different times (Crisp et al., 2001; Goclowka & Crisp, 2014). Moreover, most do not identify with just one in group or core community (Tajfel & Turner, 1979). There is a dynamic confluence of factors that influence identity and how one identifies over the course of a lifetime. For some, identities remain relatively stable across settings, situations, and stages (Kernberg et al., 2000). For others, identities evolve considerably over time based on changes in biology, psychological needs, or life circumstances (Fadjukoff, 2007; Josselson, 1996; Kroger, 2015; Kroger et al., 2010; Marcia, 2002). In its strongest form, identity represents a perception of the self as a coherent whole comprised of many integrated and intersecting parts (Gill, 1997; Kernberg et al., 2000).
The overarching consensus in the psychological and social sciences is that identity is consciously formed and socially mediated. Hoover et al. (1997) eloquently stated that “identity grows and is nurtured or frustrated in a complex bonding of self and society” (p. 21). Identity development has cognitive, social, and psychological components. Factors, including age, maturity, personality, gender, personal motivation, and social influences impact whether, when, and how identity is formed (Berzonsky, 2004; Berzonsky & Adams, 1999; Dunkel et al., 2008). Contemporary research suggests that identity development is cultivated through ongoing cycles of self-exploration, integration, and unification that persist across the lifespan (Cramer, 2004; Josselson, 1996; Kroger, 2015; Grotevant & Cooper, 1998; Oyserman, Elmore, & Smith, 2012; Sharma & Sharma). Beginning around adolescence and extending throughout adulthood, individuals come to ascribe meaning and value to specific traits, labels, or affiliations based on messages received from family, culture, community, and the larger society. These messages and meanings, both positive and negative, reflect the underlying attitudes, expectations, values, and norms that must be internally evaluated and negotiated into the concept of one’s self. It is through this dynamic process – in deeply examining the sameness versus differentness between self and others – that individuals come to understand who they are and where they fit. Ultimately, it is through this process of identity development that people grow into awareness of their characteristics and categorizations that both set them apart from each another and help to bind them together.

**Identity Development Theory**

Several theories have been developed to encapsulate identity development. Each provides a paradigmatic structure for analyzing and explaining ways in which people grow into awareness
of themselves. The following is an overview of the theoretical evolution of identity theory and
the overarching models that have driven identity research. The discussion will begin with a
review of the seminal theories of the 20th century that have formed the foundation of identity
theory, including the contributions of Freud, Erikson, Mahler, Marcia, and Bronfenbrenner. The
relevance of these theories to disability populations will be provided for each. This will lead into
a discussion of post-modern theories of identity development, including those that pertain to
multicultural and minority groups. This background will underscore the psychological and social
perspectives that have influenced how we understand identity development today and aid in
contextualizing disability identity theory, and specifically Gill’s theory, for purposes of this
study.

Seminal Theorists

Freud

Interest in identity can be traced back to Sigmund Freud. Freud (1856-1939) was an
Austrian born neurologist who is most well known for being the father of modern psychology.
Freud has had significant influence over the field of psychology, proposing theories on the
unconscious mind and human behavior that have formed the foundation of psychoanalysis and
continue to infiltrate our western society today. Freud’s Psychosexual Theory, which he
introduced in the early 1900s, is foundational to identity theory development, as it was the first
framework set forth to describe the intrapsychic processes that underlie personality development
and psychological functioning (Fiore, 2011). The Psychosexual Theory consists of five
developmentally progressive stages that span the period from birth through adolescence: oral
(birth-age 1), anal (ages 1-3), phallic (ages 3-6), latency (ages 6-12), and genital (ages 12 and
up). Each stage is associated with a specific erogenous zone that presents a developmental task to be achieved. Freud posited that personality formation is driven by primal instincts for pleasure and shaped by how developmental tasks or conflicts are consciously and unconsciously processed and resolved at each of the five stages. Healthy personality is formed when there is a balance between physical drives and social expectations, which leads to independence, self-control, interpersonal competence, and maturation (Boyd & Bee, 2006). Freud believed that maladaptive behaviors or other psychological dysfunction in adulthood stem from unmet needs or unresolved conflicts during these early stages of development.

Freud’s theory is primitive in that it focuses on personality development as a purely internal and largely subconscious process (Silverman, 2017). It fails to consider social, cultural, and other extra-personal factors that impact human development as a relational process. Moreover, Freud has been criticized by many as sexist. His theoretical work was likely influenced by bias and other European ideals of his day, including capitalism, urbanization, secularism, and individualism (Cushman, 2011). This narrow conceptualization limits theoretical relevance across diverse populations and experiences, and thereby offers essentially no cross-over to explain personality development as it pertains to people with disabilities. Still, Freud’s work is valued as a theoretical cornerstone of both psychology and identity development research.

**Erikson**

Erik Erikson (1902-1994) was a German American developmental psychologist who was one of the leading psychoanalysts of the 20th century. He is well known for his humanist theory of psychosocial development and coining the phrase *identity crisis*. Erikson contributed groundbreaking research to identity theory with his comprehensive lifespan model of
psychological development. Erikson’s work seemed a quantum leap ahead of Freud, as it expanded well beyond the Freudian focus on behavioral dysfunction and biological drives and examined ways that the normal self could grow and adapt throughout all life stages. Erikson’s theory on psychosocial development was novel in that it was the first to frame human development within a social context. Erikson believed that personality and identity development were relational processes influenced by interactions with others and the environment. Erikson was also among the first theorists to discuss the impact of culture on psychological development. He offered consideration for the ways in which development unfolds in unique ways among individuals of various ethnic and cultural backgrounds. This concept is theoretically relevant to identity development in disability and other diverse populations.

Erikson’s (1968) theory of psychosocial development is a stage model that consists of eight age-specific stages. Erikson identified these stages as: Trust versus Mistrust (birth to 12 months), Autonomy versus Shame/Doubt (ages 1-3 years), Initiative versus Guilt (ages 3-6 years), Industry versus Inferiority (ages 6-12 years), Identity versus Role Confusion (ages 12-18 years), Intimacy versus Isolation (20s through early 40s), Generativity versus Stagnation (early 40s through mid-60s), and Integrity versus Despair (mid-60s to the end of life). Like Freud, Erikson described a psychological conflict at each of these stages that must be successfully overcome for mastery of skills that support healthy personality development. Failure to resolve conflicts at each respective stage results in a poorly developed self-concept. This may make a person prone to psychosocial difficulties, including managing feelings of anxiety, low self-esteem, shame, guilt, inadequacy, loneliness, depression, and despair (Malone et al., 2016).

Most contemporary identity theories have roots in Erikson’s stage model, as it was Erikson who first directly addressed identity formation as an essential life task. Erikson directly
theorized that identity development occurred in the Identity versus Role Confusion stage. This stage is characterized by self-exploration when adolescents try out various roles and social groups to learn more about who they are and where they fit. Individuals who are successful at this stage emerge with a solid sense of self that helps them to stay true to their beliefs and values even in times of adversity. Those who struggle with identity development, whether due to low commitment to personal growth or a reduced ability to engage in opportunities that promote self-discovery, may struggle to develop a coherent sense of self in adolescence that can carry them with confidence into young adulthood and beyond.

Erikson’s theory was particularly groundbreaking in advancing identity theory research for opening the window to explore how multiple aspects of personhood (e.g., ethnic, religious, ideological, and occupational) that span a variety of social domains become integrated to form a unified and coherent sense of self. This theoretical framework supports the examination of diverse identities, including disability-related identities, which are largely influenced by extra-personal and relational factors. Still, identity development of people with disabilities is complex and requires examination that extends beyond the scope of an Eriksonian framework (DeHaan & Schulenberg, 1997; Gill, 1997; Goossens, 2001). People with disabilities represent a heterogeneous population that spans all racial, social, and cultural groups. They are also a marginalized minority group that has been laden with the deleterious effects of longstanding prejudice and stigma. This presents challenges to a person who must internally reconcile and synthesize aspects of disability to form a single, unified identity that remains consistent across life stages.
Margaret Mahler (1897-1985) was a Hungarian-born American psychiatrist, who much like Erikson, emphasized the development of the self within the context of interpersonal relationships. Mahler is most well-known for her contribution to ego psychology with her Separation-Individuation theory (1968). This theory consists of three developmental stages that span birth to 24 months of age: Normal Autistic Phase (birth-1 month), Normal Symbiotic Stage (1-5 months), and Separation and Individuation Stage (5-24 months). Mahler posited that very young children formulate a concept of self through early attachment experiences with their mother (or primary caregiver). According to Mahler, both the positive and the negative interactions that children have with their mothers during the first years of life significantly impact their psychological development. Healthy psychological development that leads to independence and a solid sense of self requires a secure attachment between children and their caregivers. Children who do not receive consistent and responsive care from their mother develop an insecure attachment that may lead to deficits in interpersonal functioning, adjustment difficulties, and susceptibility to serious psychological disorders later in life.

Independence is an important aspect of Separation-Individuation theory. Mahler posited that a secure attachment between mother and child is needed for children to separate from their mothers to foster growth toward independence. Mahler’s conceptualization of independence is problematic when considering its application to people with disabilities. The child’s or mother’s disability is an important factor surrounding independence that may alter their bonding dynamics. Depending on the disabilities involved, these factors may include physical limitations (e.g., a parent’s inability to independently care for an infant; differences in a child’s ability to
achieve developmental milestones), mental limitations (e.g., psychiatric conditions that impact the emotional availability of the caregiver), or socially induced ones (e.g., limited access to resources that support children or parents with disabilities; prejudicial attitudes or practices) (Andrews & Ayers, 2016). Independence must be assessed and supported relative to the capacity and needs of both the mother and the child when disability is involved.

Marcia

James Marcia is a Canadian psychologist who is well known for expounding on Erikson’s concept of identity development. Marcia first introduced his Identity Status theory in the 1960s. The theory structures identity development using four identity statuses: Identity-Diffusion, Identity-Foreclosure, Identity-Moratorium, and Identity-Achievement. These statuses are not sequential, and although they have their roots in adolescence, they may extend well into adulthood. Like Erikson, Marcia theorized on identity formation in relation to intrapsychic crises and growth in adolescence. Unlike Erikson, however, Marcia did not limit identity development to a single crisis or psychological task. Rather, he used a lifespan development model to conceptually describe identity formation as a dynamic, self-driven process that is expressed through the dimensions of exploration and commitment. According to Marcia, identity development occurs in relation to levels of active exploration and commitment across multiple life domains, including career, religion, social roles, and interests. This exploration nourishes commitments that lead to the development of stable personal and social identities (Marcia et al., 1993).

There are aspects of Identity Status theory that stand out as important to consider in assessing its applicability to disability populations. For instance, the requirements of self-
direction and autonomous decision-making in identity achievement may be especially problematic for people with disabilities. Historically, people with disabilities have been denied their right to opportunities, supports, and services that enable them to direct the course of their lives (Burch & Rembis, 2014; Nielsen, 2012). Institutionalization, discrimination, and other social barriers have precluded individuals with disabilities from engaging in many aspects of work and community life. These barriers not only impact the level and extent to which these individuals are able to access and participate in activities that prompt exploration, but they also imply which identities are deemed socially acceptable, available, and appropriate for people with disabilities. Additionally, Identity Status theory assumes a level of cognitive and psychosocial functioning that is needed for identity achievement. People with disabilities, whether due to the type or significance of disability, may require additional support or guidance to maximize functioning in these areas. It is possible that identity formation may be a developmental task that is simply not appropriate or relevant given disability-specific characteristics.

Bronfenbrenner

The work of Russian-born American psychologist Urie Bronfenbrenner (1917-2005) further propelled the multidimensional understanding of identity development. Bronfenbrenner is most well-known for his Ecological Systems theory (1979). This theory posits that human development is shaped by dynamic interactions between a person and multiple levels of their environment. Bronfenbrenner used a nested systems approach to conceptualize how person-environment interactions occur across five ecological systems: the microsystem, mesosystem, exosystem, macrosystem, and chronosystem. A series of concentric circles are used to illustrate the interaction of these systems, beginning with the individual at the center circle and extending
outwards to circles that represent social systems of increasingly expanding levels. Systems most immediate to the individual (e.g., family, school, peers) extend outward to those that have a broader scope of influence (e.g., community, media), and finally to the last layer that represents the overlaying culture, social values, attitudes and ideologies that encircles the totality of an individual’s environment. This circular model draws emphasis to the interconnectedness and interdependence among individuals and social influences that frame human development and the identities that they claim.

More than any other of the foundational theories discussed thus far, Ecological Systems theory seems to offer the most useful framework to explore disability identity development. Bronfenbrenner did not explicitly address disability; however, his model properly positions disability as an issue to be explored within the context of the physical and social environments. Examining identity development within this framework allows for an emphasis on the multiple factors and perspectives that exert influence over a person’s understanding of disability and what it means for them. This is important, as attitudes and beliefs are social agents that direct responses to disability. They play a role in either contributing to, or helping to eliminate, the environmental and attitudinal barriers that fracture people with disabilities apart from unity with the self and unification with society (Gill, 1997; Olkin, 1999; Olkin & Pledger, 2003).

Disability and Postmodern Identity Theories

Identity theory continued to evolve during the second half of the 20th century. This period marked the post-modern era when identity development research expanded to include multicultural perspectives and an emphasis on identity development within social groups (Cushman, 2011). Disability as a unique identity also emerged in the rehabilitation research
during this time (Forber-Pratt & Zape, 2017). This emergence coincided with the disability rights movement, which was an important catalyst for sparking interest in disability as a unique identity. The disability rights movement, which gained footing in the United States in the 1960s, supported a perceptual shift from thinking about disability as a medical problem to framing it as a social one (Rembis, 2018). Like other civil rights movements of its day, the disability rights movement was incumbent upon radical demonstrations, political protests, and a spirit of unrelenting resolve to confront prejudicial attitudes and systems of oppression in the fight for equal rights (Longmore & Umansky, 2001; Rembis, 2018). The disability rights movement brought people with disabilities into public view and challenged dominant perceptions of disability by drawing attention to the fact that individuals are handicapped not by their disabilities, but by a society that views them as “less than,” defective, and having a life not worth living (Olkin & Pledger, 2003). As disability rights activists and cross-disability group were mobilized into action, the shared experience of disability became their source of collective strength and empowerment. It was through their enduring unity that they illustrated disability as an aspect of the self that can be embraced, proudly displayed, and deeply valued; and, people with disabilities as a group with a community, culture, and identity all its own.

The Influence of Social Identity Theory on Identity Development

Identity theory and social identity theory were the major theoretical contributions to identity research during the 20th century. These theories frame identity development as a complex relational process by placing emphasis on social interactions, including the roles that people assume and the groups to which they belong. Although neither identity theory nor social identity theory directly address disability, both theories contain components that align well with
disability-related factors. Identity theory and social identity theory are complementary in structure, and as such, are often combined to form a general theory of development of the self (Stets & Burke, 2000). Differences among the core components of the theories will be discussed here individually, as they create unique perspectives for exploring identity development and disability-related factors.

Identity theory represents a family of views that center around the idea that identities are both formed and self-defined based on roles that individuals occupy. Individuals are said to occupy a role when two conditions are fulfilled. First, their behavior is accordance with the expected behavior of the role; and second, when they are able to access external resources to maintain the functions of the role (Stets & Burke, 2000). People assume as many roles as groups to which they belong. Although these roles are individually determined and self-defined, the meaning and behavioral expectations of roles are socially determined (Hogg et al., 1995).

Individuals come to develop a sense of who they are through the process of assuming roles and internalizing the societal messages associated with the roles. Identity theory may help to explain why people – even those with the same disability – may come to very different realizations about what disability means. For example, a person who has grown up with messages about disability as a personal defect may internalize messages of shame, embarrassment, and guilt and, therefore, reject a positive disability label or a disability label all together. Conversely, a person living with disability who has had plentiful interactions with positive role models with disabilities may internalize messages of resilience, adaptability, and empowerment. This individual may come to know disability as a desirable personal trait, and as a result, come to proudly identify as disabled.

Tajfel and Turner (1979) proposed another dimension to identity formation with social identity theory by introducing the concept that group membership and intergroup dynamics
influence perceptions of the self. Social identity was defined as “a person’s knowledge that he or she belongs to a social category or group” (Stets & Burke, 2000, p. 225). According to social identity theory, social identity is formed through a psychodynamic process by which people classify themselves in social categories based on comparisons with how their characteristics (e.g., gender, religious affiliation, ethnicity, or disability) either set them apart or bind them together with the characteristics of larger groups (Tajfel & Turner, 1985). This process of social categorization, identification, and comparison results in the formation of an identity that distinguishes between an “us” and a “them” – as well as an “in” group and an “out” group.

Social identity is a powerful social mechanism for self-definition. It provides a means by which people can express who they are and where they fit in their social environment. It also heavily influences the attitudes and actions of individuals to reflect the standards, expectations, and behavior of the “in” groups with which they identify (Tajfel & Turner, 1985). While the positive identification with an “in” group is an important source of self-esteem and belonging, social identity theory also posits that the status of the “in” group is only maintained through competition with the “out” group. This can create tension between groups that gives way to prejudicial views that result in segregation, marginalization, and harmful stereotypes (Tajfel, 1979).

Social identity theory can be used to attempt to explain the hostile social climate that people with disabilities must navigate in the process of forming a comfortable identity. Disability has historically been categorized as a socially marginalized “out” group – one that has been vehemently rejected from the normative culture of society. Therefore, identifying as a member of a disability group means that one must also internalize the stigma and oppression that have accompanied the label of disability. Adding to the tension is that most people with disabilities
learn about disability, and what it means to be a person with a disability, from their families, teachers, and members of the medical community who do not have disabilities (Gill, 1997). Rather than teach the value of disability, these individuals tend to focus on the need to overcome, minimize, or hide the disability in order to “fit in” and function successfully in society. This causes significant confusion and distress for people with disabilities who must internally resolve the conflict between what they can do or can become and the assumptions and expectations that society has placed on them (Salazar & Abrams, 2005). This can have a profound negative impact on an individual’s self-concept (Appleton et al., 1997) and psychological health (Holmbeck & Devine, 2010; Sales, 2000). Therefore, in examining disability identity development, it is critical to consider factors surrounding social identity, particularly as they relate to the ability of people with disabilities to form connections with others with disabilities who may model positive identification with disability.

Minority Models of Identity Development Research

Disability identity research has grown from elements of these seminal identity theories and has gained even greater momentum with the expansion of identity development models of minority group populations. Identity models of racial and ethnic minority populations (Cross, 1971; Helms & Carter, 1991; Sue & Sue, 2013) have been the cornerstone to the development of disability identity models in that they were the first to consider the impact of oppression, stigma, prejudice, and discrimination on the formation of self-concept and group belonging (Gill & Cross, 2010). The concept a minority group has its roots in sociology. Schaefer (2011) defined a minority group as “a subordinate group whose members have significantly less control or power over their lives than members of a dominant or majority group have in over theirs” (p. 245).
According to Wagley and Harris (1958), a minority group is distinguished by five characteristics: (a) unequal treatment or less power over their lives, (b) shared physical or cultural traits, such as language or skin tone, (c) involuntary membership in the group, (d) awareness of subordination, and (e) high rates of in-group marriage. Racial, ethnic, and religious groups, such as African Americans, Native Americans, and Jews, have long been recognized and studied as minority groups. In contrast, other groups, including LGBTQ+, women, and people with disabilities, have more recently been recognized as minority populations based on distinguishing elements that highlight their lack of power and diminished status in society (Rosenblum & Travis, 2000). The shared experience of oppression, which has resulted in minority groups being disproportionately affected by poverty, violence, discrimination, poor health, and other disadvantageous conditions (Karlsen & Nazroo, 2002), deems research with minority populations critical to promoting equality, justice, and wellness in society.

People with disabilities are a minority group who, while sharing the distinguishing features of other minority populations, stand out for several other unique characteristics. Foremost, people with disabilities are the largest minority group in the world, representing over an estimated one billion people worldwide (World Health Organization, World Report on Disability, 2011). In the United States alone, it is estimated that 1 in 4 individuals – or approximately 26% of the country’s population – have some form of physical and/or mental condition that significantly impacts their daily life functioning (Centers for Disease Control and Prevention, 2019). People with disabilities are also a unique minority group that any individual can join at any time. Some in the disability community have used the catchphrase “Temporarily Abled-Bodied” to refer to people without disabilities, underscoring the eventual change of function and ability that all individuals must face over time (Marks, 1999). Moreover, disability
is a universally shared experience—one that crosses all ethnic, racial, religious, geographic, social, and economic boundaries.

Despite the commonality and prevalence of disability, society has not historically perceived the prejudice that individuals with disabilities face as comparable to that of other disenfranchised populations (Schroeder, 2015). Prejudicial attitudes against individuals with disabilities have long been justified by dominant societal views that life with a disability is a life not worth living (Olkin & Pledger, 2003). The deeply engrained beliefs surrounding disability have been resistant to change, thus perpetuating harmful societal attitudes that equate the lived experience of disability with degradation, dependency, and helplessness. This has caused much intrapsychic tension for people with disabilities who internalize these societal messages as well as the associated oppression (Hammar et al., 2009; Salazar & Abrams, 2005). It is for these reasons that maintaining perspective of people with disabilities as a minority group, especially in disability and rehabilitation research, is essential to properly frame disability-related issues as social issues.

Given the shared characteristics between disability groups and other minority groups (Rosenblum & Travis, 2000), the discussion will now focus on theories foundational to identity research in minority populations. The models of Cross (1971), Sue and Sue (1990, 1991) and D’Augelli (1994) are prominent theories in the psychological literature that have significantly expanded ideas around identity formation across racial, ethnic, and LGBTQ+ populations. Each of these theories present unique conceptual insights that are salient to exploring identity development in disability and diverse minority populations. They can be appreciated as important catalysts to the genesis of disability identity theory. The following discussion of these models, including their application to disability, will round out the theoretical introduction to
identity development research and set the stage for a thorough discussion of the literature on models of disability identity development.

Foundational Models of Minority Identity Development

Cross

William Cross, Jr. is a theorist and researcher who laid the foundation for racial identity psychology. Cross is well known for his nigrescence model (1971), which is considered the seminal model of Black identity development (Vandiver et al., 2002). Cross posited that the formation of a Black identity unfolds across five sequential, developmental stages: pre-encounter, encounter, immersion or emersion, internalization, and internalization-commitment. Cross combined the fourth and fifth stages in 1991. According to the model, identity is formed through a process that leads an individual, first, into full awareness of the oppression and racism that they face as members of a racial minority group; and, later toward an internalization and vibrant expression of their Black heritage and culture. Cross (1991) stated that “the internalization marks the point of dissonance resolution and reconstruction of one’s steady state, personality, and cognitive style” (p. 230). Thus, the nigrescence model frames identity development not only as movement towards embracing one’s Blackness, but also as movement towards a deeper understanding of what it means to be Black in society.

The nigrescence model highlights an important parallel between the identity development of people who are Black and the identity development of people with disabilities. Both share similar experiences as members of marginalized minority groups who have been subject to cruelty, stereotyping, and societal exclusion (Agmon et al., 2016). Cross addressed the importance of reconciling the intrapsychic tension caused by the internalization of oppression.
and prejudicial attitudes much like well-known disability theorists, such as Gill (1997). Both Cross (1971) and Gill (1997) theorized that healthy identity formation involves the ability to assimilate to the dominant culture while simultaneously developing individualism and keeping proudly rooted in one’s minority group culture. These models call attention to the process by which individuals internally negotiate aspects of their sameness and differentness and, ultimately, achieve unity of self and unity with others.

**Sue and Sue**

D. Sue and D.W. Sue (1990, 1999, as cited in Wing Sue & Sue, 2008) introduced the Racial/Cultural Identity Development model (R/CID) to explain how individuals of racial minority cultures come to understand themselves in relation to the self, others, and society. Although the R/CID model was originally developed for racial and ethnic groups, it stands out in the identity development literature for its application to diverse minority populations, including women, LGBTQ+, and even people with disabilities (Abrams & Salazar, 2005). Sue and Sue posited that identity formation occurs across five stages: *conformity, dissonance and appreciating*, *resistance and immersion, introspection, and integrative awareness*. These stages are developmental in nature whereby individuals must achieve stage-specific tasks prior to progressing to the next. The R/CID model mirrors many of the same themes revealed in Cross’s (1971) model, such as confronting racism and prejudice, and growing into an identity that is firmly rooted in pride in one’s own culture while embracing that of others. The R/CID model, however, is a much broader model is comprised of stages applicable to many minority populations.
Not surprisingly, the R/CID model contains components that may help to explain aspects of identity development in people with disabilities. There are several stages that offer particularly salient components for consideration. For example, detachment reactions that are common in the initial conformity stage when people of racial/ethnic minorities avoid interactions and affiliations with their own cultural groups are behavioral responses that are also seen in disability groups. Most evidently, this is exhibited when people with disabilities try to “pass” as nondisabled or intentionally avoid association with others with disabilities due to fear of being stereotyped or belonging to an “out” group (Brune & Wilson, 2013). Dissonance and appreciating is another of the R/CID model stages that present direct cross-over to disability populations. An important component of dissonance and appreciating is a confrontation with, and questioning of, the stereotypes, beliefs, and attitudes that are representative of false perceptions assigned by the dominant group to the group of one’s racial/ethnic origin. People with disabilities are propelled into similar experiences of questioning when they encounter others with disabilities who defy or smash social stereotypes about disability. Such encounters may force people to confront their own biases and attitudes about disability and help them to reconstruct a new understanding of what it means to be disabled in society. The last of the R/CID stages, integrative awareness, is the most impactful stage for racial/ethnic and disability groups alike. This stage emphasizes the importance of uncovering, embracing, and integrating all aspects of oneself – both those that are in accordance with societal standards and those that are not – to foster authentic expression and healthy connections with others and society.
D’Augelli

Anthony D’Augelli is a pioneering psychologist whose research centered around sexual orientation and human development. D’Augelli is best known for his Homosexual Lifespan Developmental model (1994), which he later expanded and renamed the Model of Lesbian-Gay-Bisexual (LGB) Development. This model has served as a theoretical backbone in academic research and clinical practice with LGBT+ populations (Goodrich & Brammer, 2019). It stands out among preceding identity development models for how it resisted social norms toward heteronormativity and emphasizes the fluidity of sexual orientation (Clark & Caffarella, 1999; Goodrich & Brammer, 2019) The tenet of the Model of LGB Development is that identity development is a life-long, development process that is influenced by the environment, biological changes, social relationships, and situational context (Clark & Caffarella, 1999; D’Augelli, 1994a, 1994b). The model describes identity development as consisting of six processes: (a) Exiting a heterosexual identity, (b) Developing a personal lesbian, gay, or bisexual identity status, (c) Developing a gay, lesbian, or bisexual social identity, (d) Claiming identity as an LGB offspring, (e) Developing an LGB intimacy status, and (f) Entering an LGB community. D’Augelli identified three interrelated variables that underlie identity formation across these six processes. The complex interplay among these variables drives the development of one’s identity around sexual orientation. Individuals may enter and exit phases at different times, multiple times, or not at all based on various personal and social factors.

The Model of LGB Development broke ground in identity development research by providing a comprehensive framework to highlight the experiences of LGBTQ+ groups that, like disability groups, are still in the early stages of achieving equal rights and social acceptance.
(Marks, 2006; Meyer, 2016). The theoretical structure of the Model of LGB Development is built around the presence of persistent barriers and biases, which makes it a useful framework for exploring aspects of identity development in people with disabilities who are subject to similar forms of prejudice and stigma. One notable strength of the Model of LGB Development is in how it is nuanced to mirror the diverse experiences of people who are LGBTQ+. It is interesting to note that the model’s processes draw attention to the considerable overlap between LGBTQ+ and disability groups. For example, the process of “coming out,” which may seem unique to people who are LGBTQ+, is similar to the “coming out” experience described by some with disabilities – especially those whose disabilities are not apparent or less apparent – who reveal an aspect of disability which they had been previously kept hidden due to fear of judgment, stigma, or shame (Mauldin, 2018; Titchkosky, 2001). D’Augelli (1994) does not address how identity is formed among those negotiating intersecting identities (e.g., gay and disability). This is an important issue to factor into assessing the model and its applicability on both individual and population levels. Nonetheless, the Model of LGB Development offers a useful template for examining and guiding disability identity theory development for its emphasis on the influence of the biological, social, and cultural environments in a highly stigmatized population.

**Contemporary Models of Disability Identity Development**

**Introduction to Disability Identity Theory**

The models of identity development discussed this far laid fertile groundwork for disability identity research to take root. Much like identity theory of other minority groups, disability identity theory is a burgeoning area of research interest (Forber-Pratt, Lyew, Mueller,
& Samples, 2017). Unlike other minority groups, however, disability identity research has been much slower to evolve (Forber-Pratt et al.). There are unique aspects of disability that combined with the limitations of existing models and measures has made advancing disability identity theory and establishing consensus among scientists difficult (Forber-Pratt et al.). Still, the prevalence of disability across populations and findings from the small, but growing, body of literature on disability identity point to the need for deeper exploration of the process by which individuals come to form meanings and identities around disability (Darling, 2003; Dunn & Burcaw, 2013; Gill, 1997; Hahn & Belt, 2004; Mogensen & Mason, 2015; Ostrander, 2008).

Prior to delving into a discussion of disability identity models, the following three unique aspects of disability will be presented for their influence on individual experiences with disability and advancing disability identity research: disability-related stigma, disability multidimensionality, and barriers to the inclusion of people with disabilities in research. Addressing these points will aid in contextualizing disability identity within a conceptual framework that emphasizes its social construction and identifies potential barriers preventing the participation of individuals with disabilities from disability identity research.

Foremost to recognize is the influence of persistently high levels of disability-related stigma. Although disability rights activists of the Independent Living and Disability Rights movements pushed for a radical shift in understanding and framing disability in relation the political and social barriers that people with disabilities face (Darling, 2003; Fleischer & Zames, 2011; Shapiro, 1993), beliefs that people with disabilities are broken, feeble-minded, and discardable have dominated societies and echo in our social landscape today. People with disabilities have long been regarded as a “burden” or “threat” to society and these beliefs have been used to justify the unequal and horrid treatment of people with disabilities that can be
vividly traced back for centuries. Forced deportation (Foucault, 1965, p. 46), mass 
institutionalization (Fleischer & Zames, 2011), and compulsory sterilization (Rowlands & Amy, 
2017; Zampas & Lamackova, 2011) of people with disabilities are some characteristic examples 
of the dehumanizing atrocities that have been woven into the fabric of disability history. 
Fragments and forms of these abuses continue to persist, in some form, around the globe today. 
People with disabilities are still viewed and used as objects of charity, pity, and even 
demoralizing inspiration. Many are locked away, sent away, or dependent on services from the 
very systems that limit and oppress them. Overt evidence of this can be seen in the 
disproportionately high rates of incarceration among individuals with disabilities (Reingle et al., 
2015; Schlanger, 2017; Vallas, 2016), the institutionalization of the most vulnerable and poor 
disability populations (Burghardt, 2015), and inequities in access to health care (Havercamp & 
Scott, 2015; Krahn et al., 2015), employment opportunities (Bonaccio et al., 2019), housing (Koh 
& Restuccia, 2018), transportation (Bezyak et al., 2017), and other supports (e.g., assistive 
technology) needed for community engagement (Agree, 2014; Reed, 2008). Asserting the value 
of people with disabilities is incumbent upon dismantling the structures that systematically 
disempower them and exclude their voices for change (Mladenov, 2016; Schriner, 2001). Thus, 
the struggle to accelerate social progress for people with disabilities continues and must be 
appreciated here for how it presents as an underlying theme that binds the lived experiences of 
all people with disabilities together.

Another important aspect of disability – one that adds significant complexity to the 
development of identity theory – is that it is a multidimensional social construct. No two people, 
even those with the same disability, experience disability in the same way. Differences in how a 
condition or disorder manifests within an individual interacts with numerous other factors,
including the person’s physical environment, relationships, personality traits, health, socioeconomic status, and culture, to result in a high degree of variability in adaptation and functioning (Chan et al., 2009). Moreover, unlike other minority group characteristics like race or ethnicity that a person is born with or into, disability is a defining characteristic that can develop and manifest under a variety of circumstances at any point across the lifespan. For example, some individuals are born with a disability while others acquire one from injury or illness later in life. Some people have “sometimes” disabilities, such as chronic illnesses that wax and wane, while others have conditions that remain relatively static, or change or worsen over time. Another notable factor is that most individuals with disabilities, whether their disabilities are congenital or acquired, are not surrounded by family or peers with disabilities from whom they can learn about disability and model (Wendell, 1996). Therefore, individual responses to disability are largely determined by the beliefs and biases that have been passed down from family, teachers, and the mainstream culture. These groups tend to reinforce negative views of disability rather than those developed from affirming interactions with a core disability group (Gill, 1996; Shakespeare, 1996). The vast differences in how people formulate ideas about and respond to disability impact how disability is individually conceptualized and personally experienced. This aspect of multidimensionality has created barriers to developing disability identity models that encapsulate diverse disability experiences and allow for generalizability of findings across larger disability groups (Forber-Pratt et al., 2017).

A final point must be made to address challenges to the inclusion of people with disabilities in rehabilitation research. It is widely understood that people with disabilities are largely underrepresented or excluded from health sciences studies (Rios et al., 2016). Even when research is focused on disability and people with disabilities, there are several factors that present
barriers to participation. Examples of such barriers include a lack of transportation, inaccessible buildings or locations that are difficult to access, study-related materials that are not available in an accessible format or at an appropriate language level, and the use of measurement instruments that have not been adapted for specific disability populations (Rios et al., 2016). There are additional accessibility concerns for people who have disabilities that cause them to be socially isolated or institutionalized (e.g., in nursing homes) and those with high support needs (e.g., people who use augmentative communication devices or those with severe psychiatric disabilities). Their voices and experiences, representative of highly marginalized disability groups, remain largely absent from the rehabilitation research (Forber-Pratt et al., 2017).

An elimination or mitigation of these barriers requires strict attention to promoting accessible research design. This is achieved, on the most fundamental level, by applying principles of Universal Design and providing accommodations (e.g., interpreter, changes in the mode of response or how information is presented) or modifications (e.g., administration of alternate tests) when needed, and especially to foster inclusion of individuals with the most significant disabilities (Andrews, 2019; Beail & Williams, 2014; Harniss et al., 2007; Rios et al., 2016). Increasing researchers’ competence in the areas of disability-specific etiquette, knowledge, and culture are other important components of access and inclusion. These steps not only improve researchers’ skills, but they help to build trusting bridges with the disability community that aid in developing positive rapport and reducing research-related fears and biases (Andrews, 2019). Last, and most importantly, designing and conducting research that promotes inclusion, equality, and justice for people with disabilities cannot be achieved without direct evaluation and feedback from people with disabilities (Andrews 2019; Goodley & Lawthorn, 2010; Hammel et al., 2016). Although there is a strong push for participatory action research
design, few studies in the disability literature show evidence of full and direct implementation of its principles (Hammel et al., 2016). It is only by way of critical input and guidance from people with disabilities that rehabilitation research can evolve to support community inclusion, self-empowerment, and personal liberation.

**Emerging Models of Disability Identity Development**

Emerging models of disability identity are among the most recent theoretical advancements in contemporary rehabilitation research. Several models of disability identity were identified in a comprehensive review of the literature. The most prominent include Gill (1997), Putnam (2005), Gibson (2006), Caldwell (2011), Dunn and Burcaw (2013), and Forber-Pratt and Zape (2017). Some models, like those of Gill (1997), Putnam (2005), Gibson (2006), are more frequently cited in the literature. However, all the models are in formative stages, as none have been rigorously tested or widely adopted (Forber-Pratt et al., 2017). This has created barriers to advancements in disability identity theory and presents significant limitations to the application of the models to clinical rehabilitation practice.

Testing the existing models is one way to aid in strengthening the theoretical basis of disability identity research. As Dunn and Burcaw (2013) stated, disability identity scholarship is “more speculative than either theoretical or empirical” (p. 154), therefore it is important to develop a criteria-based framework to guide assessment of the models. There is no research available that provides standards or guidance for empirically evaluating models of identity development in disability research. However, this researcher identified five foundational variables illustrative of a structurally complete framework predicated by fundamental aspects of the social model of disability. These variables include: (a) the model is comprised of well-
developed stages, domains, or themes; (b) the model has been constructed with consideration for the influence of stigma and attitudinal barriers; (c) the model is structured to explore diverse experiences with disability; (d) the model can be formally tested with the lived experiences of people with disabilities; and, (e) the model aligns with contemporary aims of rehabilitation research to advance the status and empowerment of people with disabilities. In analyzing the models with attention to these variables, strengths and limitations of each will be made clear, as will an argument for the importance and value in empirically testing Gill’s (1997) model.

**Early Models of Disability Identity Development**

Early attempts at establishing frameworks for disability identity played an important role in initiating model developments. Livneh (1986) introduced one of the first models of disability identity development with his five-stage model of adaptation to disability. The model consists of a series of stages that bear striking resemblance to the stages of acceptance of death as presented by Kubler-Ross (1968). Livneh’s model is essentially obsolete, however, as its conceptualization of disability as a personal tragedy that must be “overcome” can be sharply criticized for how it directly clashes with the values of disability culture. Subsequent to Livneh, Charmaz (1994, 1995) made significant contributions with some of the earliest qualitative research on disability identity. Charmaz’s findings also led to the development of a model. Her model is distinguished for how it pointed to positive identification with disability. Charmaz structured her model within a medical model framework that failed to bring full attention to societal factors that influence self-perceptions of disability. Moreover, she did not factor in the influence of connections to the disability community, which have been found to be a critical component of healthy disability
identity development (Caldwell, 2011; Dunn & Burcaw, 2013; Gibson, 2006; Gill, 1997; Hahn & Belt, 2004; Putnam, 2006).

The models that follow the early work of Livneh (1986) and Charmaz (1994, 1995) have added considerable structure and depth to disability identity research. The six models selected for inclusion in this discussion represent prominent models in the disability identity literature. Each model is theoretically distinct and structurally complete. Equally notable is that these models present well-formed stages, domains, or themes that have origins in a social or minority model understanding of disability. This construction satisfies the first two variables that justify further empirical investigation. It also renders the models useful in stimulating research that examines the ways in which disability identities are shaped and formed amidst a variety of psychosocial factors. For purposes of clarity and comparison, the selected models of disability identity development will be categorized according to one of three theoretical structures: stage models, domain and status models, and thematic models. An overview and critical analysis of each will follow.

Contemporary Models of Disability Identity Development

Stage Models

Gill. Gill presented her model on disability identity integration and development in 1997. She developed her model from years of clinical work with people with disabilities and framed disability identity as a process that encompasses four distinct types of integration. Gill defined these integration types as: coming to feel we belong, coming home, coming together, and coming out. Coming to feel we belong is about individuals with disabilities integrating into society. It centers around the process by which people come to form a comfortable disability identity
despite negotiating a society that has normalized their exclusion. *Coming home* is the second type of integration. Here, Gill draws attention to the importance of connections with others with disabilities in achieving a sense of belonging. Gill’s (1997) summed up the sentiment behind the phrase “coming home” with the following statement: “The description of the experience that I find most interesting and that I hear often these days—especially who discover the pleasures of such companionship after years with it—is the simple and poignant phrase, ‘coming home’” (p. 43). *Coming together* is the third form of integration. Gill examined how society’s expectation that individuals reject their disabled parts to assimilate into the dominant culture leads them into an emotionally severed state of disintegration. Developing a stable and coherent identity requires a resolution of this conflict—an acceptance and a celebration of both sameness and their differentness—to develop a sense of psychological wholeness. The last type of integration defined by Gill is *coming out*, which “allows the real self and ideal self to reach congruence” (p. 45). People with disabilities who have reached the point of “coming out” have achieved an internalized sense of congruence that supports authentic expression and more full engagement in society.

Gill’s model cemented the empirical growth of disability identity research and models. Her model, in many ways, was groundbreaking. Gill herself identifies as a person with a disability, so she unearthed a novel perspective on how people come to form meaning and identities around disability. Most significantly, Gill presented the first model of disability identity development from a purely social model perspective. Unlike preceding frameworks, Gill’s model removed the burden of “molding oneself into a form that is deemed ‘acceptable’ in the sight of society” off the shoulders of people with disabilities. Gill’s model was also the first to introduce group identity as an integral component of positive identification with disability.
This expanded the understanding of disability identity development as a process that includes the role and function of the disability community. Moreover, Gill’s model is theoretically structured to appreciate diverse experiences with disability, including the experiences of people with congenital disabilities, acquired disabilities, and those with chronic illnesses. This supports an expansive examination of identity development across a broad range of disability groups and within a framework that aims to empower and celebrate people with disabilities.

Gibson. Gibson (2006) developed a three-stage model of disability identity development and described identity formation as a process that unfolds across the lifespan. She proposed a straightforward model that consists of three stages: passive awareness, realization, and acceptance. Gibson theorized that identity development begins, for most who are born with disabilities, in childhood. At the first stage, defined as passive awareness, the intense focus on attending to a person’s medical needs dominates their experience with, and conceptualization of, disability. Lacking at this stage is consideration for the social aspects of disability and opportunities for exposure to role models with disabilities. Later, around adolescence or young adulthood, individuals enter the realization stage at which point they begin to see themselves as someone who has a disability. This personal realization of “differentness” is associated with a variety of emotional responses, ranging from anger and self-pity to concerns to intense efforts to over-compensate for disability. The third and final stage of Gibson’s model is acceptance. Upon reaching the acceptance stage, a person has embraced disability as a positive, integrated aspect of their self-concept. For many at this stage, connections with the disability community are solidified through involvement in disability advocacy or activism work.

Gibson’s (2006) model can be appreciated for its dedicated focus on the psychosocial aspects of disability identity development. This helps to shift attention to important societal
aspects that factor into identity formation. The lifespan approach is also particularly helpful in explaining how disability identity unfolds and evolves over time. More so than other models, Gibson’s model is directed to the identity development of those with congenital or early-onset disabilities. Additionally, the stages of the model appear somewhat prescriptive to people who meet certain “standards” of disability. For example, an individual who fits Gibson’s model would be assumed to have access to medical care, a solid support system, and the ability to engage in the community. Research shows that people with disabilities often experience deficits in one or more of these areas that are fundamental to the model. As such, Gibson’s model may help to explain the disability identity development of some people with disabilities; however, it is limited in its applicability to explore the identities of diverse disability populations.

**Domain and Status Models**

Putnam. Putnam’s work is an important contribution to disability identity development for its approach to exploring disability identity from a purely sociopolitical perspective. Her model is specific to the identity development of people with disabilities who are politically engaged in the disability community. Putnam (2005) identified six domains, each of which contain subsequent subdomains, that frame political identity development: *self-worth, pride, awareness of discrimination, common cause, policy alternatives,* and *engagement in political action.* These are domains rather than phases or steps, therefore there is no sequential or progressive nature to their construction. The first three domains are person-centered and internally formed. These domains highlight the psycho-emotional process by which a person rejects negative views of disability and comes to embrace their own inner value and that of the disability community. The remaining four domains of the model focus on the communal aspects
of disability. In these domains, Putnam draws attention to the importance of people with disabilities coalescing around common causes to fight discrimination and impact policy change. Putnam argues that it is through striving together towards shared goals of access and equality that individuals grow into cohesion with other members of the disability community and into alignment with their own disability identity.

Putnam’s model advanced disability identity research by responding to the need for a conceptual framework to explain “the attitudes and beliefs that psychologically link people with disabilities to one another for the purpose of political activism” (Putnam, 2005, p. 188). Putnam’s model is valued for how it provides a paradigm to explore the direct association between disability activism and disability identity. Empirical studies, such as those of Hahn and Belt (2004) and Caldwell (2011), that explored this association have produced compelling evidence to suggest that strong disability identities are rooted in a personal commitment to social justice. The domains identified by Putnam are rooted in this spirit of activism that calls attention to the overlaying theme that the social environment is often more disabling than the disability. Although Putnam’s model is theoretically tailored for only a small fraction of people who are politically active in the disability community, this theme bears significance across universal experiences of disability.

Forber-Pratt and Zape. Forber-Pratt and Zape (2017) established the Model of Psychosocial Identity Development for individuals with disabilities. This model is the newest contribution to the disability identity development literature. Forber-Pratt and Zape’s research centered on disability identity in young adults who represent a generation that has grown up alongside legislative advances that pushed for the equality and inclusion of people with disabilities. Their findings led to the development of a model of disability identity development
that is comprised of four developmental statuses: acceptance status, relationships status, adoption status, and engagement status. These statuses are descriptive, but not unduly directive. They represent important areas of psychosocial growth and engagement that envelope identity formation for people with disabilities at various points throughout their lifetime. In this way, the model resembles a roadmap of identity development that highlights landmark components while allowing fluid movement through the psychologically rich terrain.

Forber-Pratt and Zape’s (2017) model shares many of the same theoretical features of preceding models (see Caldwell, 2011; Dunn & Burcaw, 2013; Gill, 1997; Gibson, 2006; Putnam, 2005), including an emphasis on the role and function of interactions with others with disabilities in positively integrating disability into the self-concept. Unique to the model is how it emphasized the significance of people with disabilities becoming role models and mentors for each other, which Forber-Pratt and Zape characterized as a hallmark feature of the engagement status. This introduced a new form of peer connection that is not directly addressed in other models. An apparent limitation of the model is related to its applicability. Forber-Pratt and Zape developed their model from a single study of 17 college students. Although the study participants cited a variety of physical and mental disabilities, which supports use of the model with diverse disability populations, the sample size was very small and findings are representative of a specific subset of people with disabilities, especially with regard to age, education, and level of community engagement.

Thematic Models

Caldwell. Caldwell (2011) formed his model from research with a small sample of disability leaders and activists. His findings reveal four themes that underlie disability identity
development: resistance, connection with the disability community, interconnections with the broader disability movement, and bonding with social justice and interdependency. The first theme, resistance, describes individuals having a perception of disability as a characteristic that sets them apart from society. In response, they may struggle with feelings of shame or make attempts to hide or minimize their disability. Connection with the disability community is the second theme. This theme involves increased interactions with the disability community. These interactions help to strengthen a person's appreciation for the “positive and enriching aspects of disability” (Andrews, 2019, p. 98). This second theme marks a juncture in which a person begins to grow in disability acceptance and pride. The third theme of the model is interconnections with the broader disability movement. This theme is grounded in connectedness and solidarity with others who have disabilities. Self-reflecting on one’s own biases and stereotypes about disability is an important component of this theme, as it allows a person to extend their reach to include the larger disability community, including those who may be left out of the movement. The last of Caldwell’s themes is bonding with social justice and interdependency. Here, people with disabilities fully identify as members of a marginalized social group. In doing so, they recognize their interdependence on others with disabilities as well as those of other minority groups that share common experiences of oppression.

Caldwell's (2011) model is infused with a strong flavor of disability activism that resembles the model of Putnam (2005) and other disability identity theorists (see Gill, 1997). Caldwell emphasizes interconnectedness with the disability community as fundamental to disability identity development. This brings attention to the positive influence of shared experiences with disability in forming a solid sense of self, however, as it has been previously argued in an analysis of Gibson’s (2006) model, not all people with disabilities have the
capacity, ability, or desire to be engaged in the disability community, especially in a political sense. Caldwell’s model, comparable to Putnam’s (2005), attempts to explain the disability identity development of a minority portion of people with disabilities, but it is not useful for the vast majority of those living with disability. This is empirically limiting, as disability identity is important to the psychosocial health of people with a broad range of disability types, especially those with non-apparent disabilities (e.g., chronic illnesses, psychiatric disabilities) who are typically left out of disability rights activities.

Dunn and Burcaw. Dunn and Burcaw (2013) used narrative identity research to qualitatively explore disability identity development. Narrative identity is defined as “the internalized and evolving story of the self that a person constructs to make sense and meaning out of his or her life” (McAdams, 2011, p. 99). It is a useful tool for exploring complex psychological phenomena. Dunn and Burcaw did not set out to introduce a new model. Rather, their research objective was to examine published narratives of people with disabilities from a variety of sources (e.g., books, articles) to look for illustrations of key themes previously described in the empirical literature as associated with disability identity development. Their research resulted in identifying evidence for the following six themes: communal attachment, affirmation of disability, self-worth, pride, discrimination, and personal meaning. Dunn and Burcaw provided excerpts of their findings for each of these themes. They argue that narratives, such as those that they examined, provide the detailed data that are a critical to broadening perspectives of disability identity development.

Dunn and Burcaw’s (2013) established a framework that highlights personal meaning derived from one’s own experience with disability as critical to identity development. Their use of narratives is effective in broadening the empirical landscape to include diverse experiences.
with disability. Narratives have been found to be particularly useful for exploring identity changes that occur with acquired disabilities and chronic illness (Ellis-Hill et al., 2008; McAdams, 2001). Ellis-Hill et al. (2008), for example, found that survivors of stroke negotiated changes in self-concept and reformulated their identities by re-creating their life stories to include disability. This is also helpful because many existing models have been constructed with a focus on people with early-onset disabilities or on those with ties to disability culture (Caldwell, 2011; Gibson, 2006; Putnam, 2005). Moreover, narrative research is a methodological approach that brings the lived experiences of people with disabilities into the light. In this way, Dunn and Burcaw support goals of rehabilitation research to empower people with disabilities and allow their voices to drive the research process. Still, their framework lacks the structural specificity of other models, so while it is possible to gather data to support the themes, it is more difficult to directly test.

Empirical Investigation of Gill’s Model

This preceding review and analysis of the existing models lend strong support to Gill’s model of disability integration and development. Most notably, this model is the only one that satisfies all five variables previously presented as necessary to justify further empirical investigation. These variables include: (a) the model is comprised of well-developed stages, domains, or themes; (b) the model has been constructed with consideration for the influence of stigma and attitudinal barriers; (c) the model is structured to explore diverse experiences with disability; (d) the model can be formally tested with the lived experiences of people with disabilities; and, (e) the model aligns with contemporary aims of rehabilitation research to advance the status and empowerment of people with disabilities. Gill provided a solid theoretical
framework that is appropriately nuanced, yet broad enough to be applicable to diverse disability populations. The model maintains the theoretical space needed to explore the experiences of people across a wide spectrum of disability backgrounds, from disability activists to those who might not yet identify with the label of disability. Gill’s model, like the other models, is rooted in the social model of disability. This researcher contends that Gill’s shared experience as someone with a disability has supported the construction of a model that is particularly powerful at focusing on the psychosocial aspects of identity development. This focus affirms the rights of people with disabilities to individuate and evolve, to be included and proud. Gill’s theory attests to a spirit of inclusion and empowerment that is a model for all others.

A comprehensive review of the literature did not reveal any former studies that test Gill’s model. As such, this will be the first research study to do so. Accordingly, the scope of this study will be limited to an investigation of the first type of disability identity integration, defined by Gill as *coming to feel we belong*. This first integration type is foundational to the model because it illustrates the initial move toward positive identification with disability. The remaining three integration types are incumbent upon achievement of this first integration type. An investigation of *coming to feel we belong* will explore how one’s membership to a marginalized disability group has impacted their self-perceptions of disability, their views of themselves, and their interactions in society.

As part of her discussion of *coming to feel we belong*, Gill addressed the significance of the Americans with Disabilities Act for people with disabilities in asserting their rights to access and equality. This law paved the way to the societal inclusion that is the hallmark of Gill’s first integration type. Still, laws are not enough and people with disabilities must continue to navigate a society that is engrained with negative views of disability. They must come to integrate all
parts of themselves – those that are disabled and those that are not – in pursuit of authentic wholeness. Through *coming to feel we belong*, Gill clearly asserts that the development of an affirming disability identity requires that individuals arrive at a place, from deep within, where they not only believe that they *can* belong, but that they, indeed, *should* belong. Gill poignantly finalized her discussion of *coming to feel we belong* by stating the following: “We have also dared to place the blame for not ‘fitting in’ more on the creators of restrictive environments, roles and occupations, and less on ourselves” (p. 42). So marks the transformative point of arrival at the beginning of the journey back to oneself.

Disability Identity Research of People Who Are Blind

Disability identity development has been studied in mixed disability populations (Forber-Pratt et al., 2017). This research identified three studies in a comprehensive review of the literature that specifically explored disability identity development in people who are blind. Most recently, Gibson et al. (2018) conducted a quantitative study that examined the relationship between gender, duration of vision loss diagnosis, and disability identification. The researchers developed a scale to represent Gibson’s (2006) three-stage model of disability identity development. Results from their analysis did not point to any significant differences when comparing participants’ mean scores on the scale with their gender and age of diagnosis. Their findings did, however, confirm many insights offered by the rehabilitation research, including that people with congenital disabilities tend to have more positive self-concepts (Bogart, 2014; Hahn & Belt, 2004) and higher self-esteem (Nario-Redmond et al., 2013) than those with later-onset disabilities.
The second study identified in the literature was done by Pinquart and Pfeiffer (2013) who conducted a large-scale quantitative study with a sample of German adolescents. They set out to determine if there were differences in the identity development of adolescents with vision disabilities versus those without vision disabilities. They also investigated differences in identity development between adolescents who were blind versus and those with low vision. Their results suggested that there were not significant differences between the identity development of adolescents with or without vision disabilities. Similarly, there were no significant differences in levels of identity development between participants who were blind versus those with low vision. Results did, however, suggest that levels identity exploration and commitment in participants with vision disabilities varied based on several factors, including the availability of social support, length of vision disability, and severity of vision loss.

The third study was a quantitative study conducted by Zapata (2018) that aimed to test the reliability and validity of the Personal Disability Identity Scale (PDIS; Hahn & Belt, 2004) and its correlates. Zapata tested the scale using online surveys with a sample of 206 adults with retinitis pigmentosa (RP). The PDIS is a two-factor model comprised of denial of disability and affirmation of disability. Multiple linear regression was used to measure several variables, including personal disability identity, general self-efficacy, mobility tool use, age at diagnosis, education level, and demographic variables against these factors. One major finding from the study was that lower denial of disability predicted higher general self-efficacy in RP. Although a blind population was used to test the scale, few conclusions could be drawn from this study in terms of how psychosocial aspects factors associated with living with RP influenced the identity development of the participants. This shortcoming is an illustrative example of the value of qualitative research methods in exploring disability identity development as a complex social
phenomenon. The ability to clarify, explicate, or supplement with qualitative data is important to the validity and reliability of the study (Creswell, 2013) and supports a more emancipatory approach to inquiry that keeps people with disabilities at the center of research (Hartley & Muhit, 2003; Stone & Priestly, 1996).

Summary of the Importance of the Study

As this literature review has established, disability identity development is an important, yet severely underexplored, area of rehabilitation research. Studies on disability identity have been vital to allowing researchers to more thoroughly understand the multitude of dynamic factors that influence how people with disabilities come to understand themselves and their interactions with society. Moreover, the lack of well-validated models of disability identity development has severely limited theoretical advancements to further empirical growth in this area. This study aimed to address this shortcoming by beginning the process of formally testing models of disability identity development. This researcher argues that Gill’s (1997) model is a theoretical pillar of disability identity literature and one that offers a solid framework to justify further study. Testing Gill’s model in a sample of individuals who are blind will address two urgent needs. First, it will further empirical investigation of Gill’s model – a model that has been highly valued in disability scholarship and evaluated in this review to be a strong framework of disability identity development. Second, it will contribute rich data to further research on disability identity development, especially as it relates to the experiences of people who are blind. This information is needed to support vital efforts to improve the psychosocial wellness of people with disabilities and more thoroughly understand the unique experiences of people living with vision loss, especially because they represent one of the most prevalent disability groups in
the United States and around the world (Erikson & VonShrader, 2020). This study will bring lived experiences of disability into the light. Throughout, it will remain guided by the voices of people with disabilities and be aligned with principles of participatory action research. Obtaining these stories will support aims of rehabilitation research to examine, enlighten, and empower.
CHAPTER 3

METHODOLOGY

Study Design

This research study used qualitative research methods to explore how various psychosocial factors and experiences impacted the disability identity development of people with congenital blindness. These data were intended to inform the researcher about the extent to which the thematic components of Gill’s (1997) first type of disability integration (i.e., *coming to feel we belong*) aligned with the lived experiences of people who are blind. An extensive review of the rehabilitation literature had shown that the process by which people come to integrate disability into their sense of self is a highly individualized process that unfolds across the lifespan (Forber-Pratt et al., 2017). Thus, a person-centered research approach that provided for a longitudinal perspective of growth and change was needed to support a thorough examination of individuals’ experiences with disability identity development. This study used a narrative research method known as Life Story Interview to gather data in the form of the self-narrated life story. Life Story Interview is recognized as a highly effective research tool in identity research for how it supports a holistic approach to learning how people come to understand themselves (Atkinson, 2010). Furthermore, its methodological template provides for a flexible, participant-driven process. This aligns well with both the unique needs of disability populations and principles of participatory action research. The following section will provide a
descriptive overview of the qualitative research methods selected for this study and discuss their empirical value in driving advancements in disability identity research.

Qualitative Research in Disability Identity Development

Qualitative research is at the foundation of the growing body of literature on disability identity. In fact, a systematic review of the literature revealed that approximately 75% of studies on disability identity development are purely qualitative in nature (Forber-Pratt et al., 2017). The rationale for this overwhelming preference for qualitative research methods is reflective of the advantageous conditions they offer for a thorough investigation of disability identity. Foremost among these is the ability of qualitative methods to elicit rich and nuanced data that simply cannot be captured through quantitative means alone (Creswell, 2013). Disability identity development is a complex phenomenon. As such, qualitative methods are necessary to explore it as a dynamic, intrapsychic process. Moreover, as disability identity development is an emerging area of research interest, there are virtually no well-validated measures or fully developed theories of disability identity that exist (Forber-Pratt et al., 2017). Qualitative methods have been the primary means by which researchers have been able to examine disability identity and prompt its theoretical growth. Patton (1990) discussed the importance of qualitative research in areas such as this in which “little work has been done, few definitive hypotheses exist, and little is known about the nature of the phenomenon” (p. 131). Thus, qualitative methods are a vital component in disability identity research. They help to establish its empirical foundation in a way that underscores the lived experiences of people with disabilities in health sciences research (Hartley & Muhit, 2003).
Narrative Research

Narrative research is a qualitative research method that “aims to explore and conceptualize human experience as it is represented in textual form” (Salkind, 2010, p. 869). Narrative research is unique among other forms of qualitative research for how it highlights storied experience. Stories are endemic to the human experience; constructed and impassioned to help people make sense of, and reveal meaning in, who they are and how the pieces of their lives fit together (Atkinson, 1998). Narrative research is a powerful research tool that has wide-ranging applicability across many academic disciplines. Stories have been used in the anthropological and social sciences for even longer than can be formally recognized (Atkinson, 2002). In the field of psychology, the empirical application of story can be traced back to Freud (1957, 1958) who psychoanalyzed case study narratives as part of his identity research (Atkinson, 1998). Narrative inquiry has since served a primary role in advancing other areas of psychosocial research. Stories help make “the implicit explicit, the hidden seen, the uniformed formed, and the confusing clear” (Atkinson, 1998, p. 7). They are an invaluable means to exploring complex, social phenomena. Narrative research also provides an opportunity for participants to assume a self-directed role in the research process. It provides a forum for people to be fully visible and fully heard. This is an empowering opportunity for people, such as those with disabilities, who are socially marginalized, isolated, or silenced.
Life Story Interview

Life Story Interview is a methodological approach to narrative research that is rooted in storytelling. Life Story Interview uses a person’s self-narrated life story to unravel and reveal the subjective essence of a person’s life. Atkinson (1998) defined the life story as:

the story a person chooses to tell about the life he or she has lived, told as completely and honestly as possible, what is remembered of it, and what the teller wants others to know of it, usually as a result of a guided interview by another. (p. 8)

The power of the life story is not only contained within the experiences or events that individuals choose to tell, but in the beliefs and sentiments that are communicated and the insights and meaning that have been drawn from their experiences. The propensity of the life story to reflect how a person sees themselves and how they want others to see them makes it one of the most effective research tools in the social and psychological sciences for exploring the self and identity development (Atkinson, 1998).

Life Story Interview as a research method is both an art and a science. The science of Life Story Interview is evidenced by its straightforward methodological approach. Researchers use a series of questions to gather data related to either a specific aspect of a person’s life story or their life story in its entirety. The art of Life Story Interview is in how the researcher plans and directs the interview. Different researchers use different approaches and conduct the interview in their own way. Participants also contribute to the artful nature of Life Story Interview. The manner and style in which people tell their stories are uniquely their own. Some people are natural storytellers who provide vivid details and descriptions; others may need more time in thought or may be careful and deliberate in expression. Additionally, life stories can take on a variety of forms, ranging from oral narrations, written entries, and photographs to more creative
forms such as song and poetry (Atkinson, 1998). These diverse aspects of Life Story Interview require a high degree of flexibility on the part of the researcher to effectively adapt to the needs of participants so that they can freely tell their stories. They also highlight the usefulness of Life Story Interview as a research method that seems to naturally accommodate for disability. Its methodological template supports participants of diverse backgrounds and abilities in assuming an active role in developing and delivering their life story. This ability of individuals to participate in their preferred manner and/or using an accessible format is pivotal to promoting the empowerment of people with disabilities as well as the veracity of the data.

Life Story Interview and the Present Study

Life Story Interview was selected as the research method for this study for how it rigorously supported the study’s objective to drive an in-depth exploration of how disability identity unfolded in a small sample of people with congenital blindness. Life Story Interview has been identified as a highly effective research tool to examine how individuals come to respond to the question “Who am I?” (Atkinson, 1998). This is precisely the question that guides disability identity research and the purpose of this study. Life Story Interview is also methodologically beneficial because it may reveal changes in self-concept over time. The element of longitudinal growth is consistent with views of disability identity formation as a developmental task of the lifespan (Cramer, 2004; Grotevant & Cooper, 1998; Kroger, 2015; Oyserman et al., 2012). It is paramount to investigating Gill’s (1997) first type of disability integration, characterized by internal transformation toward coming to feel we belong.

Life Story Interview also complemented this study’s design within a participatory action framework. This framework aims to actively include members of the community of interest in
the design and implementation of research activities so that the research remains informed and guided by the population of interest (Baum et al., 2006; Whyte, 1991). Participatory action research has roots in the self-help and civil rights movements (Balcazar et al., 2006). It is a preferred research framework for research with disability groups and other vulnerable populations (Selener, 1997). In alignment with participatory action research, Life Story Interview is a collaborative undertaking between participant and researcher. Through Life Story Interview, participants are given free space and choice, within a research context, to tell their stories in a holistic and authentic manner. This not only allows participants to drive the interview, but it also upholds a primary objective of participatory action research to reflect more accurate depictions of people’s social reality (Selener, 1997). Moreover, the deep and meaningful self-reflections that naturally flow from the telling of one’s life story may serve as a catalyst to personal growth. Paramount to participatory action research is the capacity of research to increase a person’s recognition of their own strengths, resources, and ability to self-advocate (Balcazar et al., 2006). Life Story Interview is an especially powerful methodology for its capacity to inspire growth while simultaneously providing for in-depth exploration of disability identity development.

Procedures

The sample development and data collection procedures used for this study are illustrated in a flowchart provided in Appendix A.

Sample Development

This study investigated disability identity development according to theoretical elements of Gill’s first integration type (i.e., coming to feel we belong) in a segment of the blind
population. The study aimed for a small sample of five to eight adults who self-identified as living with congenital blindness. For purposes of this study, *congenital blindness* was defined as a diagnosis of legal blindness received before age 4 and continuing through the present. This inclusion criteria ensured that participants had experienced most life stages, from childhood forward, living with blindness. The co-occurrence of other disabilities or medical conditions aside from blindness was not automatically exclusionary. However, study eligibility was limited to individuals who self-identified blindness as their primary disability and maintained the ability to independently engage with the researcher in an in-depth interview. This study was open to a diverse pool of adult individuals with congenital blindness. There were no inclusionary criteria with regard to categorical factors such as gender, race, sexuality, educational attainment levels, and socioeconomic status.

**Sample Size**

The determination of this study’s sample size was made with consideration for the sample sizes of previous disability identity research, the objective and methodological design of this study, and the practical limitations posed by the availability of a single researcher to conduct the research. A comparative analysis of 21 qualitative studies on disability identity identified in a systematic review of the literature showed that sample sizes varied significantly. The smallest sample numbers noted were three (Kohrman, 1999; Vidali, 2007), four (Savaria et al., 2011; Valeras, 2009), and five (Mogensen & Mason, 2015; Whitney, 2006), while the largest were 57 (Megivern, 2002) and 69 (Meyers, 2014). Studies that used a purely narrative research approach had among the smallest sample sizes. These include the studies of Kohrman (1999) (n = 3), Valeras (2009) (n = 4), Valeras (2010) (n = 6), Dunn & Burcaw (2013) (n = 6), and Adler,
Lakmazaheri, O’Brien, Palmer, Reid, & Tawes (2021) (n = 13). Thus, this study’s projected sample size of 5-8 was within mid-range of past narrative studies. Moreover, researchers such as Lee, Woo, and Mackenzie (2002) argued that qualitative studies that produce highly in-depth data, such as data generated by a Life Story Interview methodological approach, typically require fewer participants.

**Data Saturation**

Data saturation was also a guiding principle in determining this study’s sample size. Data saturation is defined as the point at which “no new information or themes are observed in the data” (Guest, Bunce, & Johnson, 2006, p. 59). Most qualitative studies use the concept of data saturation to establish sample sizes (Glaser & Strauss, 1967). Samples must be large enough to be representative of multiple perceptions but small enough to avoid undue repetition of data. It is important to note that while data saturation is an important point of consideration, it does remain a debatable concept. For example, some researchers (Bowen, 2008; Morse, 1995) argue that claims of saturation are purely subjective and devoid of proof or descriptions of exactly what it means or how it is achieved. Others (Strauss & Corbin, 1998 [1990]) suggest that saturation is a “matter of degree” (p. 136), as there is always the potential for new data to emerge. Charmaz (2006) discussed the significance of researcher role in assessing for saturation explaining that inexperienced researchers might prematurely claim saturation based on data that would prompt further exploration in more experienced ones. The determination of an appropriate sample size for this research is best addressed in relation to satisfying the purpose of this study rather than establishing benchmarks to signify a stringent point at which saturation is achieved. Furthermore,
this study is merely a starting point to investigating disability identity development according to the theoretical constructed presented by Gill’s (1997) theory.

**Sampling Techniques**

A combination of selective and snowball sampling techniques were used to identify participants for this study. Selective sampling, also known as purposive sampling, is a non-probability form of sampling in which researchers rely on their own judgment to develop a sample according to how its composition aligns with the aim and framework of the study (Schatzman & Strauss, 1973). Selective sampling was important to this study because it allowed the researcher to access individuals who represent “information-rich cases for study in depth” (Patton, 1990, p. 169). In this study, the researcher was seeking to explore diverse experiences and perspectives that impact the disability identity of people with congenital blindness. Thematically central to Gill’s first type of disability integration is the idea that to develop a positive disability identity, a person must come to believe, desire, and assert their rights to full inclusion in society. Therefore, evidence of community integration and involvement with society are important criteria for this study’s sample. Selective sampling techniques were necessary to identify individuals who have had a vast array of experiences as actively engaged members of the community. This would include, for example, participation in educational, work, or volunteer activities and/or affiliation with clubs, religious organizations, or other community groups.

Snowball sampling was also used. Snowball sampling is among the most widely used sampling procedures in qualitative research (Noy, 2008). It allows the researcher to “access informants through contact information that is provided by other informants” (Noy, 2008, p. 330). Snowball sampling is a vital component to the design of this research, as allowed the
researcher access to the natural, social networks that have formed around the shared experience of blindness. Exploring the lived experiences of societal and community connectedness is central to investigating disability identity development in accordance with Gill’s (1997) theoretical framework. It also represents action on the part of the researcher to ensure that research about people with disabilities remains informed and guided by people with disabilities.

**Recruitment**

Recruitment of the sample was achieved through outreach activities with the National Federation of the Blind (NFB) and the researcher’s professional and social disability networks. Upon obtaining approval from the Research Advisory Council of the NFB, an advertisement of the study was distributed to the NFB’s members and affiliates via its national list serve. To facilitate snowball sampling, the researcher shared information about the study via phone and email to individuals in her social and professional disability networks and requested that they “spread the word.” All advertisement material (see Appendix E) used in recruitment efforts for the study used IRB-approved language and was made available in alternate format (e.g., Braille, large print, and audio). Professional document conversion services were enlisted to ensure the accessibility and quality of materials provided in alternate format. As this study collected data from participants using remote communication methods, advertising efforts extended to a national pool of potential participants.

Individuals who were interested in learning more about the study were directed to contact the researcher by phone and/or email. Recruitment efforts through the NFB yielded a large number of respondents (n = 81) whereas outreach efforts via snowball sampling resulted in a much smaller response (n = 13). The researcher scheduled a follow-up phone call with interested
respondents who self-reported that they met the inclusion criteria. The researcher used this initial interview to ensure that individuals were well-informed about the study, the commitments involved, and how their life story would be used. The researcher also collected preliminary data from respondents using a spreadsheet that tracked information related to their demographics, type and level of social involvement, communication abilities, and personal motivation for involvement in the study. This data was used to guide the researcher in evaluating the characteristics of potential participants and determine their suitability for inclusion in the study.

Sample Selection

A total of 86 people were recruited from the advertisement efforts of the study. Of these, 53 individuals satisfied the inclusion criteria and were available to participate in interviews according to the research schedule. Selection of the study’s final sample was guided by efforts to include the insights and perspectives of people who are blind from various backgrounds and walks of life. The researcher relied on her own judgment to select people who were actively integrated into their communities and expressed an eagerness to share their life story within the context of understanding its value in contributing to disability identity research. The researcher made concerted efforts to aim for a diverse sample of participants to reflect the diversity that is inherent to the experience of disability.

People who were excluded from the study included: (a) those who self-reported having other primary disabilities (e.g., people who were deaf-blind), (b) those were limited in their ability to engage in and sustain free-flowing conversation about themselves, (c) those who had limited involvement in the community, (d) those who were compelled to share their life stories for reasons that were not consistent with the purpose of the study (e.g., the interview would
alleviate a sense of social isolation or give them “something to do” during the pandemic), and (e) those whose age, racial/ethnic, cultural, or social background did not contribute to the diversity of the sample.

Informed Consent forms (see Appendix F) were sent to potential participants in their preferred accessible format (e.g., Braille, large print, audio CD, digital file). The signed forms were returned to the researcher in advance of the scheduled interview date.

**Participant Characteristics**

This study’s sample consisted of eight participants from urban or suburban communities in western, midwestern, eastern, and southeastern regions of the United States. Five participants were recruited through the NFB and three were recruited through outreach efforts with the researcher’s professional and social disability networks. These eight participants contributed to the desired diversity of the sample (e.g., age, gender identity, racial/ethnic background) and exhibited the social involvement, communication abilities, and personal motivation that aligned with a thorough exploration of the research question.

The selected sample consisted of participants whose ages ranged from 23 to 61 years old ($M = 39.6$ years; Median = 37 years). Four participants were male and four were female. There was variability in the self-described socioeconomic status of the sample. One participant stated they were of an upper middle class, three of a middle class, three of a lower middle class, and one of a “low income” level. At the time of this study, one participant was married, two were divorced, and five were single.

All participants in the sample earned at least a high school diploma. Three participants were enrolled in college at the time of this study, three earned bachelor’s degrees, and two
earned master’s degrees. Regarding race and ethnic background, two participants self-identified as White or Caucasian, two self-identified as Black or African American, one self-identified as multiracial, one self-identified as Asian-American, one self-identified as Arab-American, and one self-identified as Hispanic and Mexican American. One participant shared that they identify as a member of the LGBTQIA+ community.

There was diversity in the sample with respect to level of vision loss and access preferences. All participants were diagnosed with at least legal blindness by the age of 18 months, thereby satisfying the inclusion requirement of a diagnosis of congenital blindness. Four participants described their vision loss as “low vision” or “partial blindness” and the other four described their vision loss as “total blindness.” Six participants from the sample were integrated into the public schools for elementary and high school, one attended a residential state school for the blind for both elementary and high school, and one participant attended some school years in an integrated, public school setting and others in a segregated program for the blind. Five participants were Braille readers, while the remaining (n = 3) accessed printed material in digital, large print, or audio format. Three participants used guide dogs for mobility; the remaining five used a white cane.

Based on the data gathered during the preliminary interview with the researcher, all participants demonstrated active participation in their communities. Three individuals were college students, one of whom also worked a part-time job, and three were actively employed full-time in the community at the time of this study. Two participants had vibrant employment backgrounds but were not employed at the time of this study. Five of the participants had public profiles within the disability or blind communities. All participants self-reported that they had
access to public transportation and/or private chauffeur services (e.g., Uber, friends) and were able to independently navigate their community.

**Data Collection**

Data was collected in accordance with methodological standards of Life Story Interview (Atkinson, 1998, 2002). Participants engaged in an audio-recorded, in-depth interview with the researcher in which they told their life story. Due to the current restrictions and conditions of the COVID-19 pandemic, interviews were conducted remotely. Individuals had the option to participate in their interview either by phone or Zoom. Participants were encouraged to select the interview format that best supported their needs and provided for a private and comfortable setting. Of the eight in the sample, three participants chose Zoom and five chose phone. Interviews were scheduled at a mutually agreed upon time that was convenient for both the participant and the researcher. Additionally, participants were given the option to complete the interview in either a single session or multiple interview sessions. One participant selected to have their Life Story Interview divided into two separate sessions. The remaining participants (n = 7) completed the interview in a single session. Pauses and breaks were taken as needed to ensure participants’ comfort. No accessibility or technical issues were encountered during any of the interviews. The length of interviews ranged from 110 – 172 minutes (M = 141 minutes).

The researcher acknowledges the uniqueness of the remote fashion in which life stories were shared as part of this research project. One strength of this design was the increased accessibility of the study. For example, mobility and travel-related barriers were virtually eliminated. This opened access to study participation for some who may otherwise be precluded. It also widened the scope of potential participants in such a way that individuals who are best
suited, irrespective of geographical location, were eligible for inclusion in the study. Additionally, remote interviews allowed participants to maintain a comfortable environment and provided an added layer of anonymity and/or privacy. Life stories are personal stories, filled with moments of great joy and great pain. Interviews by phone or Zoom may have helped to promote neutral research space and authenticity in sharing, thereby minimizing the negative impact of social desirability bias and subsequently increasing the validity of the data.

**Interview Process**

Interviews conducted within a Life Story Interview framework are procedurally unique. Unlike other forms of interview used in qualitative research, Life Story Interview does not use a standardized or straightforward approach to gather data. Rather, Life Story Interview relies on a fluid and collaborative process in which participants are guided by the researcher into deep, reflective sharing at the feeling level (Atkinson, 1998). Life Story Interview is a flexible, participant-driven process. Individuals construct and share their life stories in a way that best expresses their experiences and creates meaning for them. The role of the researcher is one of active listener and observer in which they must use their understanding of what they hope to learn from individuals to guide participants through the telling of their stories. Often this requires the researcher to anticipate what questions to ask and which direction to take the interview in real-time. As Atkinson (1998) stated, “the less structure a Life Story Interview has, the more effective it will be” (p. 41). Much of the art of Life Story Interview is evidenced by the skillful conduct of the researcher in facilitating the storytelling process while not getting in its way.

The interview process designed for this study was based on the general guidelines for Life Story Interview outlined by Atkinson (1998). These guidelines provide a framework so that
data gathered help to answer the research question and represent people’s experiences in their truest form. The interviews for this study followed a thematic framework rather than a strictly chronological one. Some areas of empirical interest for this study were self-perceptions of disability, beliefs about disability, attitudinal and environmental barriers, interpersonal relationships, and experiences related to work and community life. This design allowed the researcher to thoroughly examine areas that correlated with participants’ life experiences in relation to the thematic components of *coming to feel we belong* (Gill, 1997).

The Life Story Interview is structured to cover a series of main sections, also known as *domains*, that encompass specific experiences or aspects of a person’s life. (Atkinson, 1998). There are domains that are typical to most Life Story Interviews (e.g., family of origin, education, work). The domains selected for inclusion in a study, however, should be tailored to the goals of the interview (Atkinson, 1998). As such, some studies supplement typical domains with those that are unique to the research topic. For example, Adler et al. (2021) used a Life Story Interview approach to explore disability identity in a sample of adults with acquired disabilities and included a section specific to acquiring disability. Because *coming to feel we belong* is deeply rooted in intrapersonal (i.e., existing within the individual), interpersonal (i.e., existing between persons), and social experiences, selected domains must allow for a thorough exploration of the psychosocial, cultural, and disability-related elements of a person’s life. Thus, interviews for this study encompassed the following domains: (a) family of origin, (b) early life experiences, (c) cultural setting, (d) education and work, (e) relationships and social factors, (f) beliefs about disability, and (g) disability community. *Beliefs about disability* and *disability community* were sections that were added by the researcher to address aspects of disability identity that are unique to this research project.
Consistent with a Life Story Interview, the researcher used a flexible approach to the interview process and adapted questions to the unique needs and experiences of participants (Atkinson, 1998, 2002). An interview guide (see Appendix B) was developed to provide a basic outline for the interview and the selected domains to be covered. This interview guide also contained a series of pre-selected, open-ended questions that aided in prompting participants who needed guidance in telling their stories. These questions were not intended to comprise an exclusive or exhaustive list. Instead, she selected questions during interviews ad hoc to help “guide the storyteller toward the feeling level” (Atkinson, 1998, p. 41) and to reflect on various aspects of living with disability that have shaped their understanding of themselves. Examples of questions in the interview guide include: (a) Can you tell me about one of the first times that you realized that you were blind and most others were sighted? (b) What was it like being someone with a disability who grew up in your culture? (c) What feelings does the word disability bring up for you? (d) How has society’s response to your disability influenced your beliefs about your disability? (e) What is it like for you when you meet other people who are blind or have disabilities?

To aid participants in preparing to tell their life story, the researcher contacted individuals in advance of the scheduled interview date to provide information about the interview, address accessibility needs, answer any questions, and offer guidance on how to prepare their life story. Atkinson (1998) offered some suggestions for life story preparation that can be modified for use by people who are blind. Among these include a person visualizing their life as a timeline that highlights major life events and collecting articles or items that prompt feelings or represent their life in a creative form. Individuals were encouraged to have or use any items or adaptive tools that are helpful to them during the interview process.
The researcher took two additional measures near the conclusion of the interview to ensure that individuals were active and valued participants in driving the research process. One involved the researcher providing each participant the opportunity to contribute closing remarks if they so desired. The researcher prefaced this opportunity with the following: I want to invite you to share whatever it is that you feel is important for me and others to know about you and about living with blindness. By way of this invitation, participants were given a chance to freely express any feelings, thoughts, or insights that were important to them. Additionally, at the conclusion of the interview, the researcher requested feedback from participants about the interview process. Feedback from participants was incorporated into the research process.

Accessibility

The accessibility of the interview was of prime importance through each phase of this study. Although Life Story Interview is a flexible and accommodating research process by nature (Atkinson, 1998), the researcher made concerted efforts to ensure barrier-free participation. All study-related materials were made available in the format of the participant’s choosing prior to the interview. During the interview, the researcher provided audio description and extra processing time and/or breaks to accommodate disability-related needs. Furthermore, although the researcher herself is a woman with a disability and a rehabilitation professional who has acquired extensive experience providing services for people who are blind, she acknowledged that she is an outsider to the blind community and the experience of blindness. Thus, throughout the duration of the study the researcher actively accessed her professional and social networks for guidance on best practices in relation to working with people who are blind.
Data Analysis

This study used thematic analysis techniques originally developed by Braun and Clarke (2006). Thematic analysis is a method of qualitative data analysis that involves identifying themes and exploring patterns of meanings in data sets (Braun & Clarke, 2006; Daly, Kellehear, & Gliksman, 1997). Thematic analysis is a flexible, interpretive method that can be adapted for use with many types of research that explore participants’ subjective experiences, feelings, and perceptions (Braun & Clarke, 2019). It is among the most frequently used data analysis methods in qualitative research (Guest, MacQueen, & Namey, 2012) and is considered a natural complement to narrative data for its focus on thematic development (Atkinson, 1998).

There are inductive and deductive approaches to thematic analysis (Braun & Clarke, 2006). An inductive approach involves the researcher assigning themes to the data without regard for a specific theoretical framework. This contrasts with a deductive approach in which the researcher analyzes data through the lens of existing theory or according to preexisting themes identified in other research (Braun & Clarke, 2019). This study used a combination of inductive and deductive approaches. This dual approach will allow the researcher to generate themes for purposes of formally testing Gill’s theory and allowing for the emergence of new findings to expand disability identity research. Such an approach adds explanatory power to this study that is unavailable through other data analysis methods.

Braun and Clarke (2006) identified six phases of conducting thematic analysis: (a) familiarization, (b) coding, (c) generating themes, (d) reviewing themes, (e) defining and naming themes, and (f) writing up. These phases involve straightforward procedures for organizing data into broad, categorical themes as described in Table 1.
## Table 1

**Thematic Analysis Flow Chart**

<table>
<thead>
<tr>
<th>Phase</th>
<th>Description of the Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Familiarization</td>
<td>Read and re-read the transcript</td>
</tr>
<tr>
<td></td>
<td>Make initial notes about data patterns of interest</td>
</tr>
<tr>
<td>2 Coding</td>
<td>Create codes for verbal responses across entire dataset</td>
</tr>
<tr>
<td></td>
<td>Collate data relevant to each code</td>
</tr>
<tr>
<td></td>
<td>Record codes and organize in a systematic fashion</td>
</tr>
<tr>
<td>3 Generating Themes</td>
<td>Collate codes into potential themes</td>
</tr>
<tr>
<td></td>
<td>Gather data that correlates to potential themes</td>
</tr>
<tr>
<td>4 Reviewing Themes</td>
<td>Evaluate for the alignment of themes with the codes identified</td>
</tr>
<tr>
<td>5 Defining and Naming Themes</td>
<td>Provide names and clear definitions for each theme</td>
</tr>
<tr>
<td></td>
<td>Continuing analysis to refine themes and ensure that themes reflect the overall story that the analysis attempts to convey</td>
</tr>
<tr>
<td>6 Writing Up</td>
<td>Final opportunity for analysis of themes</td>
</tr>
<tr>
<td></td>
<td>Selection of compelling illustrative examples that relate to the research question</td>
</tr>
<tr>
<td></td>
<td>Scholarly report of the analysis</td>
</tr>
</tbody>
</table>
Interviews were audio-recorded using an Olympus DM-720 digital recording device. Professional human transcription services were used to transcribe the audio data. Transcripts were printed and saved as password-protected electronic files on external USB flash drives. Copies of the transcripts were then shared with participants for review in the accessible format of their choice (e.g., Braille, digital file, large print). Participants were asked to read through their transcript to verify the accuracy of its content. They were also given the opportunity to add or revise information contained in their transcript as needed. Life Story Interview involves a step prior to data analysis known as *corroboration* (Atkinson, 1998). Corroboration is an important step in Life Story Interview not only for how it promotes the validity of the data by ensuring that an individual’s story is accurately told in the way they wish it to be told (Atkinson, 1998), but it is also a step that supports a participant-driven approach to the interview process. This is an important step that empowers individuals as active participators of research.

**Data Management**

The researcher managed and analyzed data manually. According to Basit (2003), several factors drive the decision on whether to use either electronic (e.g., NVivo software) or manual (e.g., paper and pen) data analysis techniques. Among these include the size of the project, available funding, and the individual preferences of the investigator. The researcher determined that manual data management and analysis were best suited for the study due to the modest size of the research project and her disability-related accommodation needs. Manual codebooks, white boards, and colored notepaper were used to record and organize codes, themes, and other descriptive information about the data.
Privacy Shields

Maintaining participant confidentiality remained a top priority throughout this study. The printed transcripts, external flash drives, and all study-related materials were kept in a locked file cabinet to which only the researcher had authorized access. Data were obfuscated to eliminate both direct (e.g., names, dates, location) and indirect (e.g., job title, organizational affiliation) identifiers from all personally identifiable information. Additionally, pseudonyms and other code words (e.g., “Company ABC” rather than the name of the company) were assigned to obscure the data. Despite concerted efforts to obfuscate data, the detailed nature of Life Story Interview creates challenges to anonymization (Atkinson, 1998). For this reason, only direct text or quotes from transcripts that are self-selected by participants will be made available in public reports and publications related to the study.

Data Coding and Theme Development

Data coding and theme development involved a combination of inductive and deductive approaches. The analysis was divided into three distinct phases: Phase One, Phase Two, and Disability Identity Analysis. Phase One involved inductive thematic analysis to generate themes from the life story narratives. Themes from Phase One were then incorporated into a deductive approach in Phase Two that formally tested Gill’s (1997) theory. Lastly, at the conclusion of Phases One and Two, a descriptive analysis of each participant’s disability identity was conducted in relation to coming to feel we belong. This multi-step analysis was designed to strengthen the rigor of the study while maintaining a focus on underscoring the voices and lived experiences of people with disabilities.
Phase One

Phase One involved an inductive thematic analysis approach. Phase One used a two-step process. This two-step design supported an intensive examination of the data and provided a built-in mechanism for cross-checking the analysis. The first step of Phase One involved domain-specific coding of individual narratives. Data was coded to generate themes without regard for a particular theoretical framework. Direct quotes and emblematic examples from the datasets that corresponded to generated themes were recorded. This analysis generated highly contextualized themes that remained grounded in specific aspects of the life story. (See Figure 1.) It also provided a nuanced perspective to various aspects of a person’s life experiences that influenced their views of disability and identity development.

The second step of Phase One involved coding each narrative as a single, whole dataset. Themes that were generated from this second step represented broader themes, including recurring themes or those that were found in multiple domains of the life story. Direct quotes and emblematic examples from the datasets that corresponded to generated themes were recorded. This second step of the analysis was important for how it helped the researcher to gain a holistic perspective of participants’ experiences and provided insight into longitudinal growth or change that occurred across the lifespan. (See Figure 2.)

At the completion of Phase One, the researcher conducted a cross-analysis process to check for the consistency of her thematic findings for each of the narratives. This cross-analysis process consisted of collating domain-specific generated themes from step one with the broader themes from step two. The researcher verified that themes from step one directly fit within, or complemented, themes generated from step two. No outliers were identified.
Figure 1. Example of Phase One, Step 1.

Note: This diagram depicts four themes generated from codes that correspond to a single domain in a representative participant.
Figure 2. Example of Phase One, Step 2.

Note: This diagram depicts four themes generated from the analysis of the life story narrative of a single participant.
Phase Two

Phase Two involved a deductive analysis approach to test Gill’s (1997) model. Data were analyzed to assess their fit with the five thematic components of *Coming to Feel We Belong* (integrating into society) (Gill, 1997). In preparation for Phase Two, the researcher performed an in-depth analysis of *coming to feel we belong*. This analysis involved coding each line of text of *coming to feel we belong* and creating thematic categories from the codes. From this analysis, the researcher identified five, overarching themes of Gill’s first disability integration type: (a) confronting difference, (b) social exclusion, (c) desiring inclusion, (d) asserting rights, and (e) expecting access. Each of these themes has been defined and described using supportive examples and/or direct text from Gill’s theory (see Table 2).

Thematic findings from Phase One were used to complete Phase Two. Using a process of deductive thematic analysis that resembled that used by Dunn and Burcaw (2013), the researcher identified themes and excerpts from the narratives that were illustrative of the thematic components of *coming to feel we belong*. Data that described or exemplified any of the five thematic components were marked accordingly (See Appendix C). The researcher thoroughly noted data of interest, paying close attention to data that were in direct alignment with the themes of *coming to feel we belong* and data that were in conflict.

Analysis of Disability Identity

Upon completion of Phase One and Phase Two, the researcher performed a descriptive analysis of each participant’s disability identity. This involved using findings from Phase One and Phase Two to analyze how psychosocial factors and experiences influenced how participants perceived their blindness and views of themselves. Emphasis was placed on incorporating direct
Table 2

*Thematic Components of Gill’s (1997) First Type of Disability Integration*  
*(coming to feel we belong)*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description of Theme</th>
<th>Supportive text from Gill</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confronting difference</td>
<td>Individuals with disabilities recognize their difference and confront the psychosocial implications of belonging to a marginalized social group.</td>
<td>“Both those who grow up with disabilities and those who must make sense of disabilities acquired later in life are ultimately faced with the same task: they must work out comfortable identities and social roles despite their membership in a socially marginalized group.” (p. 42)</td>
</tr>
<tr>
<td>Social exclusion</td>
<td>Individuals with disabilities experience exclusion from society, which they have been socially conditioned to endure and accept.</td>
<td>“As objects of charity or targets of professional remediation, we with disabilities have been historically trained to view ourselves as properly excluded from ‘normal’ life.” (p. 42)</td>
</tr>
</tbody>
</table>
| Desiring inclusion | Individuals with disabilities desire to be included in society and to have access to all aspects of community life. | “Children with disabilities often express the desire to attend neighborhood schools ‘with everyone else’ (p. 42)  
Adults talk about equal opportunities for employment” (p. 42) |
| Asserting rights  | Individuals with disabilities claim and exercise their rights to access and equality in society. | “Instead of hoping for a cure to restore our social value, we could assert our rights to the mainstream in spite of our impairments.” (p. 42) |
| Expecting access  | In understanding equal access as a societal responsibility, individuals with disabilities not only assert their right to inclusion but come to expect it. | “We have dared to expect accommodation for our differentness. We have also dared to place the blame for ‘not fitting in’ more on the creators of restrictive environments, roles, and occupations and less on ourselves.” (p. 42) |
quotes from the narratives in which individuals self-described their blindness and identity
development process. This analysis provided an overall assessment of the extent to which
participants’ disability identities “fit” within Gill’s (1997) theoretical description of coming to
feel we belong. As the researcher’s analysis pointed to a quasi-hierarchical structure to the five
thematic components, the disability identity development of participants was also assessed in
relation to the highest level of thematic component that was satisfied.

After obtaining a descriptive analysis of disability identity for each participant, findings
were comparatively analyzed between participants (see Appendix D). Thematic patterns or
trends were noted. Of special interest to the researcher were themes that represented
psychosocial factors or experiences that were unique to the experience of blindness.

Researcher Considerations

The researcher identified several of her own biases that she brought to this study.
Identifying and reflecting on these biases was critical for the researcher to remain attentive to
their potential influence on the research process. As a woman with a disability herself, the
researcher has faced disability discrimination, stigma, and environmental and attitudinal barriers.
Additionally, she claims a positive disability identity and is a member of the disability
community. Thus, the researcher approached this study with both a scholarly and a personal
belief that disability identity development is an important intrapsychic process that has a positive
influence on how a person sees themselves and interacts with society.

The researcher found her shared experience as a person with a disability to be an
important factor in establishing trust and rapport with participants. This shared experience
supported concerns for promoting an accessible and sensitive approach to research. However, the
researcher also recognized that her shared experience with disability had the potential to lead to an over-identification with participants. This could cause the researcher to miss or misinterpret the intention or meaning of the participant’s data. The researcher was intentional in the design of this study in selecting a disability group apart from her own to ensure distance between experiences with regard to disability type. Additionally, the researcher kept a reflexive journal throughout the research process. Journaling allowed her to reflect on her own biases and experiences throughout each phase of the study, which helped to address and minimize their potential to negatively impact the data collection and analysis processes.
CHAPTER 4

RESULTS

This qualitative study used a Life Story Interview approach to answer the following research question: How do the psychosocial factors and experiences related to the disability identity of people with congenital blindness align with the thematic components of Gill’s (1997) first type of disability integration (i.e., *coming to feel we belong*)?

As previously mentioned, Gill (1997) identified four types of disability integration involved in disability identity development. This study set out to examine the first integration type, defined by Gill in her model as *coming to feel we belong*. Gill (1997) regards *coming to feel we belong* as foundational to her theory, as it involves what are often the initial steps in the development of a disability identity. *Coming to feel we belong* focuses on the influence of a person’s interactions with their social environment in how they come to perceive disability and regard themselves. Thus, disability integration within the context of *coming to feel we belong* can be used to explain the internal process by which a person moves from feelings of difference and exclusion toward “the assertion of a right to inclusion in society” (Gill, 1997, p. 42).

For purposes of performing a complete and thorough examination of Gill’s (1997) first type of disability integration, the researcher deconstructed *coming to feel we belong* into thematic parts. The results of the researcher’s analysis suggested that there are five thematic components of *coming to feel we belong*: confronting difference, social exclusion, desiring inclusion, asserting rights, and asserting access (see Table 2). Each thematic component delineates a distinct aspect of disability integration that exerts influence over a person’s belief regarding their
inclusion in society. There is considerable interconnection and overlap among the premises of these five components. That is to say that more than one thematic component may be used to describe or categorize a particular experience or factor within this disability integration type. This interdependence typifies the dynamic interaction between a person and multiple variables of their social environment in the development of a disability identity (Darling, 2003; Dorozenko et al., 2015; Kinavey, 2006; Zhang & Haller, 2013). The researcher’s analysis also pointed to a quasi-hierarchical structure to the thematic components whereby themes sequentially corresponded to increasing levels of assertions of belonging. This structure provided an opportunity to explore each person’s disability identity development within the framework of coming to feel we belong and with respect to the type and level of each of the five thematic components.

The themes that emerged from an analysis of the data contained in each of the life story narratives allowed for an in-depth exploration of the psychosocial factors and experiences that impacted the disability identity development of people with congenital blindness. These themes were used to conduct a comparative analysis with the five thematic components of Gill’s (1997) first disability integration type. Results of this analysis are organized and discussed according to the thematic component of coming to feel we belong. The findings noted under each component are representative of prominent themes discovered across the sample of eight participants. Related tables provide a summary of the thematic results, including their frequency rates, related subthemes, and the domains of the life story in which they were contained. As disability identity development is a highly individualized process, results are best appreciated within the context of the life story. Therefore, direct quotes from narratives are included to exemplify thematic alignment with coming to feel we belong and give voice to participants’ lived experiences.
Thematic Components of *coming to feel we belong*

**Confronting Difference**

*Confronting difference* is the first thematic component of *coming to feel we belong* (Gill, 1997). A person recognizes that there is something about them – how they appear, function, move, or interact – that sets them apart from others and causes them to be pushed to the side along with others like them who cannot meet the standards. *Confronting difference* is foundational to Gill’s first integration type because for a person to integrate disability into their self-concept, they must first recognize it as a valid aspect of their life experience. It draws attention to the central, theoretical premise of *coming to feel we belong* that individuals must not only grow into awareness that their disability sets them apart from others, but that disability also causes them to be regarded as members of a marginalized social group. Therefore, the “assertion of a right to inclusion in society” (Gill, 1997, p. 42), which is the culmination of *coming to feel we belong*, is incumbent upon a person confronting the difference that results in their exclusion from society.

Results of the thematic analyses provide support for confronting difference as a primary component of disability integration. All participants described experiences in which they confronted individual and social differences due to their blindness. Although the factors surrounding these experiences were highly variable, the impact of the social environment on how participants perceived blindness and viewed themselves was universal. Findings from the analyses of this study pointed to three prominent themes of confronting difference: (a) internalizing a sense of separateness, (b) conceptualizing the meaning of blindness, and (c) awakening to self-potential. The first two themes comport with the description of confronting difference based on the analysis of Gill’s (1997) first integration type. The last theme suggests a
more expansive view of how some people may respond to a confrontation of their difference, especially when early associations with blindness are anchored in the resilience, independence, and empowerment of the blind community. Table 3 contains a summary of the results.

**Internalizing a Sense of Separateness**

The first theme that emerged in exploring Confronting Difference was *internalizing a sense of separateness*. This theme describes an internalized awareness that blindness sets a person apart from others. Internalizing a sense of separateness is more than a mere recognition of one’s difference. Rather, it involves a grappling with negative associations with blindness that cause separation from others and a separation from disability within oneself. Internalizing a sense of separateness presented as a theme of childhood in three of the life stories. It shaped individuals’ early understanding of blindness and perceptions of themselves. Several external sources of influence were identified as factors in this theme’s development, including culture, family response to blindness, school environment, and access to appropriate supports. This theme aligns with *coming to feel we belong* for how it emphasizes the disenfranchisement of people with disabilities and their marginalized status in society.

Mia’s story provides perspective into the psychosocial dynamics of internalized sense of separateness. Mia was a 32-year-old Asian-American woman with partial blindness who grew up in a culturally Korean home. Mia shared how her parents had only recently immigrated to the United States when she was born and learned of her significant vision loss. Mia shared that her parents were “devastated” and “heartbroken” by her diagnosis, and given that they spoke little English, were unable to access information to help them fully understand her condition or support her needs.
Table 3

Summary of Results from an Analysis of Confronting Difference

<table>
<thead>
<tr>
<th>Thematic Component of coming to feel we belong</th>
<th>Description of theme: Individuals with disabilities recognize their difference and confront the psychosocial implications of belonging to a socially marginalized group</th>
</tr>
</thead>
</table>

**Confronting Difference**

**Theme 1**

**Internalizing a Sense of Separateness**

Describes a person’s recognition that blindness sets them apart from others

<table>
<thead>
<tr>
<th>Narrative Frequency</th>
<th>Related Subthemes</th>
<th>Life Story Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 3</td>
<td>Influence of Culture</td>
<td>Family of Origin</td>
</tr>
<tr>
<td></td>
<td>Family Response to Blindness</td>
<td>Cultural Settings</td>
</tr>
<tr>
<td></td>
<td>School Experiences</td>
<td>Early Life Experiences</td>
</tr>
<tr>
<td></td>
<td>Access Barriers</td>
<td>Work and Education</td>
</tr>
<tr>
<td></td>
<td>Isolation</td>
<td>Relationships and Social Factors</td>
</tr>
<tr>
<td></td>
<td>Shame</td>
<td></td>
</tr>
</tbody>
</table>

**Theme 2**

**Conceptualizing the Meaning of Blindness**

Describes the process by which a person comes into more full awareness of the social implications of blindness and what it means for their life

<table>
<thead>
<tr>
<th>Narrative Frequency</th>
<th>Related Subthemes</th>
<th>Life Story Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 4</td>
<td>Family Response to Blindness</td>
<td>Family of Origin</td>
</tr>
<tr>
<td></td>
<td>Striving for Independence</td>
<td>Early Life Experiences</td>
</tr>
<tr>
<td></td>
<td>Relational Dynamics</td>
<td>Work and Education</td>
</tr>
<tr>
<td></td>
<td>Social Exclusion</td>
<td>Relationships and Social Factors</td>
</tr>
<tr>
<td></td>
<td>Connection to Blind Community</td>
<td>Beliefs About Disability</td>
</tr>
<tr>
<td></td>
<td>Role Models and Mentorship</td>
<td>Disability Community</td>
</tr>
<tr>
<td></td>
<td>Interactions with Blind Children</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fear or Risk of Social Exclusion</td>
<td></td>
</tr>
</tbody>
</table>

**Theme 3**

**Awakening to Self-Potential**

Describes the experience of discovering new meaning and hopefulness in response to blindness

<table>
<thead>
<tr>
<th>Narrative Frequency</th>
<th>Related Subthemes</th>
<th>Life Story Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>n = 1</td>
<td>Emotional Resilience</td>
<td>Cultural Settings</td>
</tr>
<tr>
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<td>Access to Resources</td>
<td>Family of Origin</td>
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<td>Freedom and Choice</td>
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<td>Role Models and Mentorship</td>
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The implications of cultural differences and limited supports amplified a sense of separateness that followed Mia around both her home and school environments. She was rarely at ease about who she was and struggled to communicate her feelings with her family. Mia stated, “As a child, I was constantly throwing tantrums because I didn’t know how to feel good. I just felt different all the time.” Mia attended an integrated public school, and although she received some vision services, she did not receive mobility training or a white cane until the seventh grade. Mia’s struggle to navigate her environment and express herself intensified her sense of separateness. The social isolation created deep, emotional angst within Mia. She shared:

I didn’t have many friends who could relate to me, so I felt really alone… I just felt like I stuck out. I certainly felt self-conscious if I hit a wall or a doorknob. I hit a window once and punctured a hole in my head. It was things like that that made me feel very ostracized as a kid…I think my one solace during that time was that my mom let me have animals in the house. Animals don’t care if you can’t see. I think that was my saving grace.

Another participant, Carmen, spoke of a sense of separateness in terms of internalizing a feeling of “wrongness” about herself. Carmen was a 27-year-old woman from Mexico who was adopted at the age of seven. Although she had been totally blind since birth, Carmen stated that it was not until she entered Kindergarten, soon after coming to the United States, that she realized that she was different from other children. Carmen recounted a vivid memory of the first time she internalized the word “blind” as a child. Carmen said that this experience fundamentally altered how she saw herself because, for the first time, she recognized that she did not fit within standards of “normal.” Carmen shared:

It was very interesting to come to the realization that I was blind. Other kids would look straight at me and I couldn’t see them back. And I’m like, “What’s wrong with me? I can’t see the people. I can’t see where it’s coming from.” I was like, I am not a normal kid.” That’s when it hit me.
The complex interaction of factors that manifest internalizing a sense of separateness was also illustrated in the story of Jayla, a 26-year-old African American woman who was born with congenital cataracts and several other vision disabilities. Jayla told of many negative memories from painful medical procedures that she underwent for her blindness as a young child. It was through these painful experiences that she grew into awareness that blindness made her different from others. Jayla stated, “That’s when I started to realize that I have to go to the eye doctor and all that stuff. I think that’s when I began to realize I’m different from everyone.” These medical experiences not only reinforced a negative association with blindness but caused her to feel apart from others. Jayla said that as a child she sometimes overheard strangers make cruel remarks or ask her mother questions, such as “What’s wrong with her?”

Jayla also felt this sense of separateness in her home environment. Although she spoke about her mother being a loving support in her life, Jayla’s father struggled to understand and process her vision loss. Confronting difference required Jayla to confront her father’s negative emotional response to her blindness. She shared, “My dad had a hard time dealing with a daughter who was visually impaired. I would knock something over and he would get annoyed with me, and then I would get upset.” Jayla perceived her blindness as a cause for her father’s frustration and she began to internalize feelings of inadequacy and shame. To cope, Jayla would frequently retreat to her room, which only intensified feelings of isolation and loneliness.

I was a shy little girl. I didn’t have good communication skills because I was in my room all the time. I was this quiet child, and then my mom worked a lot so she didn’t have a lot of time to really spend with me or my brothers, so I would make up imaginary friends.
Jayla’s social and home environments stifled her personality and misguided her understanding of blindness. Jayla later attended a state school for the blind where she not only flourished in independence, but also came to develop a deep sense of belonging and pride.

**Conceptualizing the Meaning of Blindness**

*Conceptualizing the meaning of blindness* was the second theme that emerged under Confronting Difference. Conceptualizing the meaning of blindness described the process by which a person comes into full awareness of the social implications of blindness and what it means for their life. This theme aligns with *coming to feel we belong* for how it draws attention to the oppression that people with disabilities face as members of a minority group. Conceptualizing the meaning of blindness emerged as a dominant theme of adolescence in the life stories of two participants. It was found to be mediated by four factors: family response to blindness, relational dynamics, striving for independence, and fear or risk of social exclusion.

The interdependence of these mediating factors was clearly illustrated in John’s story. John was a 42-year-old African American man with total blindness. He grew up in the deep South with his mother, brother, and extended family. Blindness was an unanticipated, new experience for John’s family. Still, John said that his family was supportive, inclusive, and made him “feel like a normal kid.” John shared: “My brothers and stepbrothers and stepsisters and my brother had me doing everything that everybody else was doing. Riding a bike, trying to skate, playing basketball, football, baseball, soccer.”

John understood that blindness made him different from others; however, it was not until later in adolescence that he fully grasped the implications of his blindness. John explained that not having contact with others who were blind and not having access to many opportunities in
his community growing up made it difficult for him to conceptualize the meaning of blindness beyond its obvious functional implications. However, this changed for John around the age of 18 when he met his mentor, Charles. Charles was instrumental in causing John to reflect more deeply on the potential implications of his blindness and what that meant for his future. John recalled a conversation with Charles that shook him at the core:

For me, the real game changer was my mentor Charles. Charles told me, “Hey, I know you’re sheltered, but you’re going to have to learn how to do things for yourself. You need to make plans and goals for yourself or you’re going to end up in a group home.”

John spoke of how the fear of ending up in a group home was “frightening” to him. He said, “without a doubt it made me realize that being blind could mean that I would end up not being part of society.” Internalizing the fear of social exclusion motivated John to start thinking about the future and making goals. One of his goals involved seeking out services from a center for the Blind. It was there that he acquired additional independent living skills and found inspiration through the success of others who were blind. John was able to use his skills and connections within the blind community to begin envisioning and creating a fulfilling life for himself.

Anna was another participant whose story details conceptualizing the meaning of blindness. Anna was a 48-year-old Caucasian woman with partial blindness due to albinism. Anna grew up in a family that had a history of vision impairments, so her parents were familiar with how to support a blind child. Anna described her mother as her role model in life and someone who helped her to develop a positive self-concept as a Blind individual. Anna shared many happy childhood memories, including memories of her experiences at a summer camp for
kids and teens who were blind. She shared that camp was a “huge” part of her life and helped her to develop a positive self-image as a blind child.

Anna’s self-acceptance and early interactions with others who were blind helped to guard her from negative associations with blindness in childhood. However, adolescence presented as a challenging time for Anna when she, for the first time, directly faced social implications of her blindness. Anna attended a local public high school where she was integrated into classes with her sighted peers. Blindness took on a new meaning for Anna when she became more aware of its impact on her independence and inclusion in peer groups. Anna shared:

I didn’t really notice my blindness much until high school when all the kids were learning to drive and doing so many things more independently. That’s when I realized that I couldn’t do those same things. That’s when I started to understand that blindness meant that I couldn’t be part of the same things that my friends were part of. It [blindness] wasn’t a big deal until there were things I couldn’t do. That was hard. I didn’t want that part of blindness.

**Awakening to Self-Potential**

*Awakening to self-potential* emerged as the theme of Confronting Difference in a single narrative. Despite this theme’s anomalous existence in the results of this study’s analysis, it presented as a compelling theme in the life story of one participant, thus suggesting its significance in examining *coming to feel we belong*.

Awakening to self-potential describes the experience of discovering new meaning and hopefulness in confronting blindness. It is representative of a positive emotional and behavioral response to a realization of blindness. Culture, family response to blindness, freedom and choice, access to resources, and connection to the blind community were identified as factors that influenced the development of this theme. Awakening to self-potential highlights the
significance of connection to the blind community in integrating into society, which aligns well within Gill’s (1997) model and thematic aspects of coming to feel we belong. However, awakening to self-potential also draws attention to positive associations with blindness that may withstand or supersede those related to oppression and marginalization that are typically characteristic of the disability experience.

Awakening to self-potential was identified in Omar’s narrative. Omar was a 23-year-old Arab American man with total blindness. He grew up in a close-knit family with his parents and siblings. Omar described his family and culture as very important influences on his life and how he saw his blindness. His family embraced blindness and taught Omar from an early age that he can choose to create his own identity. Omar did not recall a specific memory or time in his life when he first became aware that he was blind. For him, it was a gradual process of unfolding.

Blindness has always been natural for me. When I was younger, I didn’t realize that I was apparently different. But I started to realize it when people would approach me different than they would approach my peers. And I noticed this particularly from students my age when I was in elementary school. For example, I would notice sometimes the students would all be competing to help me out. I was always wondering why they don’t compete to help each other out. It took me a while to connect the dots.

Omar had many positive associations with blindness growing up. Omar’s family worked to ensure that he had access to the best schools and resources as well as to teachers and mentors who believed in his potential. Omar’s parents were also facilitators of freedom and choice in his life, which encouraged him to discover his own meaning of blindness. Omar shared:

It was always a sense of leaving it to me. I choose how to interpret my blindness. No one else chooses how to do that…So my parents did not necessarily know how I was supposed to interpret my blindness. They just knew that I’ll have to figure it out and that I should use any obstacle as a reason to grow strong.
A turning point in Omar’s understanding of blindness and his own potential as someone who is blind occurred when his family took him to his first Blind convention. Omar recounted the story:

I remember it was an early Saturday morning that my parents woke me up. I was enjoying my slumber when they said, “Come on, get up. I want to take you to this event that you might enjoy.” I told them, “I’m not interested. Let me go back to sleep. It’s a rainy Saturday, leave me alone.” But they insisted.

And I remember we drove the hour drive. My parents piled us all up in the car and we drove down to the conference. We walk into what appears to be this conference room. And I don’t know how many conventions you attend, but those things are boring, especially for a 10-year-old. So we sit down and you hear this gentleman talking about having traveled the world independently. And about having just traversed the world and seeing places where roads aren’t paved and there are no traffic laws and you still have to get across the street anyway. And I’m like, ‘Okay, why do I care to hear about some dude ranting about his travel experiences and how he hated the fact that there weren’t any traffic lights in some random town in some random country?’ And then I realized. I’m like, “Wait. This guy is blind. This guy just told me he just traveled the world and he just crossed the streets that were unpaved. Wow!”

I don’t know if you’ve ever had that feeling when something just randomly sinks in. You’re sitting there, you’re denying it, you’re not interested, you’re rejecting it. And then it just hits you. For me, it was a realization of what I could do and who I could become as a blind person.

For Omar, confronting difference involved confronting the possibility of what he could do and who he could become. His early association with blindness was anchored in an understanding of resilience, independence, and empowerment within the blind community. This was further supported by his culture and family values for connection and community. Omar’s self-awareness of his own potential grew with him into adulthood. As Omar reflected on his past, he talked about how it fostered creativity, independence, resilience, and a spirit of hopefulness. He strives to use these characteristics to give back to his community and create a brighter future.
Social Exclusion

Social exclusion is the second thematic component identified in the researcher’s analysis of coming to feel we belong (Gill, 1997). This theme describes the exclusion of people with disabilities from society, which they have been socially conditioned to endure and accept. Social exclusion highlights the influence of negative societal views of disability on a person’s belief about their right to inclusion. Gill (1997) stated, “As objects of charity or targets of professional remediation, we with disabilities have been historically trained to view ourselves as properly excluded from ‘normal life’” (p. 42). Social exclusion is a theoretically grounding component of coming to feel we belong because it addresses the marginalization, oppression, and stigmatization that impact the inclusion of people with disabilities in society.

Themes illustrative of Social Exclusion were identified in multiple domains across all seven of the narratives. Participants provided descriptive examples of social exclusion across the lifespan. Three prominent themes of social exclusion emerged from the analysis. They included (a) bullying and mistreatment, (b) access barriers to inclusion, and (c) challenges to employment integration. All three of these themes align within Gill’s (1997) model of coming to feel we belong, and specifically, within the descriptive framework of Social Exclusion. No conflicting themes were noted. Societal misperceptions and negative views of blindness were significant underlying factors of this thematic component. The theme positive peer support was found to support Social Inclusion and is presented as a significant finding for further discussion. Tables 4 and 5 contain a summary of the results.
### Table 4

**Summary of Results from an Analysis of Social Exclusion (Themes 1-3)**

<table>
<thead>
<tr>
<th>Thematic Component of <em>coming to feel we belong</em></th>
<th>Description of theme: Individuals with disabilities experience exclusion from society, which they have been socially conditioned to endure and accept.</th>
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<tbody>
<tr>
<td><strong>Social Exclusion</strong></td>
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<tr>
<td><strong>Theme 1</strong></td>
<td><strong>Bullying and Mistreatment</strong></td>
</tr>
<tr>
<td>Describes the bullying and mistreatment endured by Blind individuals in the home and/or school environment.</td>
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<td><strong>Narrative Frequency</strong></td>
<td><strong>Related Subthemes</strong></td>
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<td>Low Self-Worth</td>
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<td>Social Isolation</td>
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<td>Deriving Empathic Response</td>
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<td></td>
<td><strong>Life Story Domains</strong></td>
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<td>Family of Origin</td>
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<td>Early Life Experiences</td>
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<td></td>
<td>Work and Education</td>
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<td>Relationships and Social Factors</td>
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<tr>
<td><strong>Theme 2</strong></td>
<td><strong>Access Barriers to Inclusion</strong></td>
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<tr>
<td>Describes the physical and/or attitudinal barriers that Blind individuals encountered in their educational and social environments</td>
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<tr>
<td><strong>Narrative Frequency</strong></td>
<td><strong>Related Subthemes</strong></td>
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<td>n = 8</td>
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<td>Striving for Independence</td>
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<td>Access to Braille</td>
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<td>Beliefs About Disability</td>
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<tr>
<td><strong>Theme 3</strong></td>
<td><strong>Challenges to Employment Integration</strong></td>
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<tr>
<td>Describes the workplace barriers that Blind individuals faced in securing and maintaining employment</td>
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<tr>
<td><strong>Narrative Frequency</strong></td>
<td><strong>Related Subthemes</strong></td>
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<td>Beliefs About Disability</td>
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Table 5

Summary of Results from an Analysis of Social Exclusion (Theme 4)

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<thead>
<tr>
<th>Thematic Component of coming to feel we belong</th>
<th>Positive Peer Support</th>
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<tbody>
<tr>
<td>Theme 4</td>
<td>Describes the social groups and relationships that support social inclusion of people who are blind</td>
</tr>
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<td><strong>Narrative Frequency</strong></td>
<td><strong>Related Subthemes</strong></td>
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<td>Blind Camp</td>
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<td>Sense of Normalcy</td>
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<td>Self-Acceptance</td>
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<td>Community Belonging</td>
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<td>Barrier-Free Participation</td>
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<td>Blind Leadership</td>
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<td></td>
<td>Confidence in Self and Abilities</td>
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<td></td>
<td>Social Integration</td>
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<td></td>
<td>Personal Growth</td>
</tr>
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</table>

Bullying and Mistreatment

*Bullying and mistreatment* associated with blindness was a theme of Social Exclusion in five of the life stories. It was discovered as a theme of adolescence that was most frequently associated with school and peer group experiences. Bullying and mistreatment manifested in both overt and covert forms. It included, but was not limited to teasing, verbal harassment, ignoring, mocking, intentional exclusion (e.g., being the only person not invited to a birthday party), using someone’s blindness to play tricks on them, spreading gossip and misinformation, physical attacks (e.g., tripping, punching), and manipulating access to mobility aids (e.g., hiding someone’s white cane). Participants spoke of the severe, negative impact that bullying had on their emotional well-being, social inclusion, and views of themselves. It presented as an important theme of discussion in exploring early life experiences of ostracization and exclusion.

David was open about sharing his experience with bullying during adolescence and the psychological harm that it caused. David was a 57-year-old Caucasian male who had total
blindness due to a congenital condition in which he was born without eyes. David grew up in a home that embraced his blindness and worked very hard to ensure his access and inclusion. In retelling his life story, David lovingly talked about his “amazing” mother who helped him to develop self-worth, confidence, and independence. David joyfully recalled the time that she found a way to put bells in a baseball so that he could play with his neighborhood friends and how she learned Braille when David was very young because she wanted to be able to write letters to him as he grew. David shared:

When I would go to camp, I was the only kid whose mother sent him Braille letters. It’s unbelievable. I want to tell you, I felt like I was about ten feet tall and bulletproof. The other kids wanted me to read my mother’s letter to them because all of their letters, if they got any at all, had to be read to them by the counselors.

David also had a close relationship with his siblings. David was known in his family as “everybody’s baby” and his siblings played an active role in teaching him and caring for him. David shared, “When it was time for me to learn to walk, my sisters and my brother would take turns, putting my feet onto their feet and teach[ing] me the motion of walking.”

Unfortunately, the love and support that David received at home was not found at school. Middle school and high school years presented with extreme social difficulties for him, as his blindness made him a target of bullying. The emotional and physical attacks caused deep pain and kept him excluded from peer groups. The frequency and intensity of the bullying took a serious toll on his mental health. David shared:

It’s bad enough to be a blind person to start with. It was bad enough because there’s always going to be somebody who going to knock a blind person over or knock down another disabled person – put somebody out of his wheelchair. It always seemed to be more of that where I went to school than there should have been…They made it difficult for me to trust. It wasn’t surprising that I eventually ended up with depression. It took a
while. But, of course, it was the early 80s and especially for a boy, you weren’t supposed to admit it if you had a [mental health] problem.

David’s story highlights the deleterious impact of bullying on a person’s self-esteem, self-worth, sense of belonging. Other participants used words such as “humiliating,” “embarrassing,” “lonely,” and “shaming” to describe the torment that they endured. Mia, who endured bullying as well, bluntly stated, “Blindness as a teenager just sucked. I don’t know how else to word it or if I can word it lightly.” Sometimes the bullying involved adaptive equipment that individuals used. For example, Anna recalled a time that a student in her middle school classroom put a curse word under her CCTV only to have the enlarged text displayed for other students and the teacher to see. Anna ended up being the one scolded for this act instead of the student, saying that teachers and staff rarely intervened to stop these types of situations from occurring. John spoke of being exploited for his blindness and feeling used to satisfy others’ curiosity. He explained: “Going through school, I was the only blind person, so people were curious. They would always try to trick me or scare me. I got picked on a lot.”

Of all the participants who shared experiences of bullying or mistreatment, none spoke of having received responsive support from teachers or staff at their school. And, like David, few shared these experiences with their parents. Furthermore, when asked about whether their school had any disability awareness activities or education, none of the participants recalled ever having such opportunities. Several participants have used their very painful experiences with bullying to promote awareness of blindness and more empathic responses to disability. Some participants serve as mentors to other young people who are blind. Others have used social media and the Internet as platforms to educate others on blindness in hopes that society may understand more about blindness and be more attitudinally inclusive to people with disabilities. Mia’s words
echoed the sentiment of many others of this study when she shared, “My compassion became more and more encompassing because I struggled so much as a kid.”

**Access Barriers to Inclusion**

"Access barriers to inclusion" emerged as a theme of Social Exclusion in all eight of the narratives. Access barriers were categorized as either environmental or attitudinal, the latter of which was stressed by participants as being more pervasive and preclusive. Regardless of the type of barrier presented, it resulted in the exclusion of individuals from full and active participation in their communities. This exclusion had a negative impact on levels of independence and integration. It also affected social-emotional well-being. For instance, participants shared that access barriers incited feelings of frustration, inadequacy, social isolation, and being perceived by others as “less than” in status or value. Thus, this theme emphasized an interdependent relationship among access, inclusion, and a sense of positive regard in *coming to feel we belong*. The access barriers that were identified in this study were categorized as follows: (a) barriers to accommodations or services in education, (b) societal misperceptions of blindness, and (c) barriers to inclusive technology.

**Barriers to accommodations or services in education.** Four participants spoke in depth about barriers to effective or appropriate accommodations or services in school. All four of these participants were students integrated into the public-school setting. They described barriers to accommodations or services, such as the availability of textbooks and classroom material provided in alternate format (e.g., Braille, audio, large print), Braille training, accessible computer software (e.g., ZoomText, JAWS), and a sighted aide. The negative impact of barriers to these accommodations or services on academic performance is obvious. These access barriers
were also found to have a snowballing, negative impact on individuals’ psychosocial well-being. Participants told stories of how access barriers prevented them from participating in extracurricular activities and being included in their school communities. They also reported feelings of low self-esteem, self-worth, frustration, and loneliness as young people who had to endure, as David stated, what was a “constant battle” for acceptance and inclusion. Notable, too, was how these access barriers denied them of the opportunity to fully explore, develop, and realize their capabilities and own unique potential.

Mia’s story provides a descriptive account of the multidimensional nature of access barriers in education. Mia had a very difficult school experience—from elementary school through college—due to significant issues with obtaining appropriate accommodations. These issues negatively impacted Mia’s access to learning in the classroom and also resulted in a host of social and emotional challenges. Mia said that access barriers were constantly getting in the way of being who she wanted to be, especially in high school. She shared this story:

I remember freshman year in high school, I wanted to run cross country because I ran cross country all three years in middle school. And I had a guide in middle school – a teacher who would guide me at every race. It was awesome. It was awesome! And it made me feel like I’m actually being active. But that changed when I hit high school and wanted to run cross country again. They wouldn’t provide me with a guide. They were afraid that I would get hit by cars and things like that. So they didn’t let me run. I went to the first meeting in the fall semester and I talked to the coach and she was like, “Well, I’ll find someone for you.” And then what I actually tried to go back, they’re like, “Well, I don’t think it’s safe. We can’t guarantee that you’ll be safe.” I wanted to be someone who was athletic, but that was not an option for me.

Further complicating her access issues was that the school used Mia to provide translation services for her parents at her IEP meetings. Mia described this as being “super awkward and super awful.” Aside from the ethical concerns that this presented, Mia said that it was “very tough” to have to convey negative information about her grades when her poor
performance was directly related to accommodation issues. These IEP meetings caused Mia to feel further silenced and marginalized because she was not given the opportunity to speak up for herself or self-advocate for her access needs. Furthermore, since academic achievement was highly valued in Mia’s culture, her school challenges were not met with understanding or support at home. This intensified the struggle for Mia on both academic, psychological, and social levels. She said, “I was like, ‘Is it me? Am I bad? Am I incapable of learning?’” The access barriers had proved to have an accumulating, negative impact. Mia shared:

I had fought for accommodations to learn the dance portion of the audition and I finally got to take those accommodations and learn the dance portion three times before I actually auditioned for the dance part to make it into the show. And I ended up seeing my name on the list. I had made the show. But, immediately, because of my grade in one of my advanced placement classes, I was told that I couldn’t be in it. And all of my friends my senior year were in it. So I was like, “This is ridiculous. I’m not getting appropriate accommodations in the classroom, I have to translate for my parents, and I get punished.”

After high school, Mia continued onto college. There, she encountered similar access barriers. For example, Mia was denied accommodations by some professors who would make remarks, such as, “I won’t [provide accommodations]. That’s not how the real-world works.” Eventually, however, Mia found advisors who cared about her struggles and guided her to appropriate supports. Mia said that through their assistance and belief in her, she developed even stronger self-advocacy skills, slowly regained her self-confidence and, over time, came to discover her true capability as a student.

Another participant, William, also had experiences at school in which he felt punished for his blindness. William was a 61-year-old man who was born with partial blindness from optic nerve damage. He grew up and attended school prior to disability access laws in schools.
William told many stories of how his high school years felt “miserable” to him because they were fraught with access barriers. William vividly recalled:

I remember getting in trouble with my PE teacher my sophomore year because I wouldn’t do hurdles. I couldn’t do hurdles because I can’t see. You know, in other words, you absolutely had to do hurdles or you wouldn’t pass that portion of PE class. I can run for 20 miles, but I can’t do hurdles. And so he had me doing push-ups and then I got detention. And I was on my file at school that I’m blind. But, yeah, I got in trouble with him. I’ll never forget that…

Then I got in trouble again in my sophomore year in social studies class because I couldn’t read maps. I still can’t read maps, and I’m never going to read maps. And then I wanted to record stuff to help me take notes. And he was one of those teachers that didn’t want to be recorded. So, I was stuck to fail that class, and it wasn’t anything related to my abilities or intelligence. It was just this teacher’s attitude.

The access barriers that Jayla experienced in the public school setting eventually led to her transfer to a residential state school for the blind when she was 10. She explained, “I struggled in public school until I went to the boarding school for the blind. Then I excelled because they had high expectations of me and they accommodated me. I found out who I was as a visually impaired person.” As Jayla reflected on her time before attending the school for the blind, she spoke of how not being taught Braille or how to use a white cane were her most significant access barriers. Prior to using a cane, Jayla was severely limited in her ability to freely explore her environment. She said that it left her feeling isolated, scared, and without any self-confidence. Additionally, the public school did not provide Braille training because Jayla had some residual vision. Jayla was left to rely on large print and audio, which was limiting for her because her vision would get very easily fatigued.

These access barriers had a two-fold impact on Jayla’s childhood. First, her ability to grow in independence and autonomy was severely restricted. Second, Jayla was denied access to the mobility tools that she would later regard as the source of her empowerment, identity, and
pride. Jayla recalled a specific memory from high school that prompted a deepening of her appreciation for Braille and of her desire to become a champion for Blind children:

I really started to discover myself in tenth and eleventh grade when I was working with younger kids as part of my class at my residential school. I could only work with the kids that were print readers. I didn’t know Braille at the time and I felt really bad. I felt like I should be ashamed of myself because I can’t even communicate with the whole blind community, the Braille readers. I can’t see if they did their work right. I couldn’t help them because I didn’t know Braille.

So when I was in twelfth grade in my last year I decided to take Braille as an elective. And I really started learning Braille… I want to help others. I want to give them some of the things I didn’t get. I want to give other Blind students cane and Braille access so they can have confidence…I want to be like Anne Sullivan.

Societal misperceptions of blindness. All eight individuals in this study spoke at length about the attitudinal barriers that they faced on a nearly daily basis. It was a topic that generated much passion and concern among participants. Individuals shared the ways in which misperceptions or negative views of blindness have contributed to an attitudinally hostile climate that keeps people who are blind separated or “rightfully” excluded from society. Societal misperceptions of blindness was a theme woven into all five components of coming to feel we belong. It will be reported on separately in this section for its direct and profound impact on the social exclusion of people who were blind.

Six misperceptions of blindness were identified in an analysis of the life stories: (a) blindness is tragic, (b) blindness incurs limitations in a person’s capacity to experience the world, (c) mobility devices are restrictive and a sign of impairment, (d) blindness is inspirational, (e) blindness is weakness, and (f) blind people would choose to be cured. All six misperceptions will be included in this report to ensure that the voices of all participants are represented and heard.
The first misperception addresses society’s view of blindness as tragic or catastrophic. This misperception emerged in several life stories. Mia stated: “A common misconception is that if the diagnosis of blindness is given, it’s an automatic death sentence. That you’ll never do something great with your life.” Mia expressed deep frustration with these views, as she believed that they give society permission to “ignore us, disregard us, and pity us.” Anna, who was born in the early 70s, recalled her mother being given a very grim and grossly inaccurate prognosis for Anna’s life simply due to her vision impairment. “The doctor said that I would never walk, talk, or be productive.” Medical perspectives, such as this, that forced highly negative beliefs about the capacity or potential of children born blind were identified in four other narratives.

William talked about how he might have ended up institutionalized if his mother had not rejected society’s starkly negative view of blindness. William was raised by his single mother who herself had a physical disability from polio. William explained that his mother had experienced discrimination and stigmatization her entire life, so she had intimate knowledge of the societal barriers that her son would face. William said if it had not been for his mother’s personal experience with disability, active work in the disability community, and strong advocacy skills, he might have adopted what he termed the “pitiful and deplorable” views of disability that were prevalent all around him.

William shared that he “felt” a subliminal, negative message about blindness throughout society growing up. Although these prejudicial and stigmatizing views remained largely unspoken, William said they were highly perceptible to him through how others reacted to him. The message he felt was: “Society doesn’t want to have to deal with us or hear about us. They wanted to keep us hidden and keep us separate and go along their merry way.” William spoke
about the need to “work adamantly to prove” his competence and value in society throughout his life. As he said, “I had to prove that, yes, I do belong here. I have something to contribute.”

The second misperception is that blind people are limited in their ability to engage with the world. This misperception was identified by two participants. Carmen shared her perspective that society’s fixation on visual sight thwarts their understanding of blindness. She said that blindness does not inhibit or limit her ability to engage with the world. She shared that she does, in fact, “see,” just through different mediums than sighted people. Carmen does not view visual sight as a superior trait. She described blindness as a strength that has allowed her to engage all her senses and more fully take in the energy and details of her environment. Carmen shared that Braille awakens her imagination and described her cane as her eyes that allow her access to the world. She explained:

Oh, I love my cane…My cane is my eyes. That’s how I see things. That’s how I see the obstacles. That’s how I see the structure. Especially if I combine the cane with the hands, I can see, especially when somebody describes to me what I’m looking at and the color and everything. It’s just magnificent to me. I think it’s amazing. I can feel the world through my cane and my hands.

Carmen’s story draws attention to the third misperception of blindness, which is that mobility devices, such as canes, are restrictive and a sign of impairment. William said that some people outside of the blind community might view his white cane as a “a dreaded device” or something that he should feel “embarrassed or ashamed” to use. However, like Carmen, William fondly talked about his white cane, calling it “my eyes that actually work.” For Jayla, her white cane is not only a sign of mobility and independence, but also a source of pride that roots her in her identity as a Blind woman. Jayla said with a smile, “I feel like my cane is like a wand. Like a fairy needs a wand.”
Anna had a different perspective to share about the white cane. Anna, who has had experiences with both a white cane and guide dog, explained that she prefers to navigate her community with her guide dog because her guide dog tends to draw people in while her white cane seems to push them away. She explained:

As far as overall society, I noticed that if I have a cane, their response is more negative. But then when I have my guide dog, they are more positive. Everyone’s like, “Oh, dog!” It seems to soften everything. I think people are scared of the cane. They just don’t know how to approach me with the cane.

The fourth misperception that was identified is that blindness is inspirational. While on the surface this view may seem complimentary to some, participants explained how perceiving people as inspirational solely on the basis of blindness feels demeaning and dehumanizing. John, who is a single father of two young children, works two jobs and is active in his community. John said that he is frequently approached by strangers who make unsolicited remarks about how “amazing” it is that he works despite his blindness. John said that these comments reflect the very low expectations that society has for Blind people. They reinforce harmful beliefs that blindness makes a person incompetent, incapable, and dependent. John shared:

I tell them, “The only difference between me and you is that I’m blind and I have to figure out certain ways to do things.” People treat me like I’m such an amazing person and I try to explain to them, “I’m not amazing. I want the same thing you want. Don’t you want to eat every day? Don’t you want a roof over your head? Don’t you want to be able to take care of your family?”

They basically have that misconception that they might see on a movie with somebody fumbling around. And that’s what they think of blind people. But what they don’t understand is that just because somebody is blind, it does not automatically mean that we are amazing because we want to live life and we want to work just like you. You don’t have to tell me, “God bless me,” because I’m blind. Now, if you really mean it, that’s fine. But if you’re telling me that because I’m blind, I’m not this amazing person.
The view of blindness as inspirational is juxtaposed with the fifth misperception, which is that blindness is a sign of weakness. This misperception contributed to social exclusion through a devaluation of Blind people. Individuals in this study’s sample emphatically refuted this belief. William stated: “Society may view me as weak because I’m lacking strength in one particular area…and that’s my vision. People tend to make a presumptuous claim that having bad vision somehow makes me more vulnerable, slower, less capable, or less intelligent.” William pointed out the exceptional skills he has acquired because blindness has required that he devote himself “more fully and attentively to each and every task.” William stated, “Because of this, I am stronger at everything I do.”

Mia wanted to emphasize the adaptability and ingenuity of people with disabilities. She said, “People are innovative. People are resilient. I think that as people with disabilities and chronic illnesses, we are natural problem solvers. We are forced to adapt every single day – from the most miniscule problem to the hardest, brain-crunching problem we can think of.”

David’s story is also evidence of the tremendous strength that is witnessed in the lived experience of blindness. David developed exceptional memory and visualization skills because he did not have physical sight. These skills, combined with grit, passion, and an indomitable spirit, have allowed him to succeed and make his mark in a profession that has been traditionally regarded as profession for the sighted.

The subject of a cure for blindness was voluntarily brought up by three individuals in the sample. This subject addressed the final misperception that Blind people would choose to be cured. Participants said that most sighted people assume that they would choose not to be blind if given the option of a cure. However, they felt differently. For these individuals, blindness was described as an integral and valued part of their self-concept. For example, Jayla expressed:
“They’re working on a cure for one of my eye conditions, but what’s funny is I wouldn’t want
the cure because I feel like if I did get the cure, I wouldn’t be Jayla anymore. I’ve been like this
for so long, I’m used to being who I am.” William added, “I wouldn’t trade my experiences or
my disability for anything. It’s part of what has made me who I am.”

**Barriers to technology.** Barriers to technology were the most frequently reported type of
physical or environmental access barrier identified in this study. These barriers included access
to mainstream technology (e.g., computer software, cell phones, touch screens) that was
inclusive to blind people as well as Assistive Technology (A.T.) for people with disabilities (e.g.,
Braille notebooks, talking clocks). Mainstream technology was defined as “inclusive” if its
features and applications were designed to be usable by people without sight.

All eight individuals in the sample used A.T. daily to work and/or perform tasks of daily
living. Participants self-reported that A.T. is essential to their independent functioning. William,
for example, shared that household items, such as his talking clock and C.C.T.V. for
magnification, make it possible for him to “get on with life” by performing the common tasks
(e.g., opening and reading mail) without assistance from others. Additionally, all eight
participants stated that they also relied on inclusive technology either at home, at work, or out in
the community. Inclusive technology was highly valued by those in the sample. Carmen said that
it gives her “access to the world and to others.” For instance, seven of the eight participants
stated that social media was an important part of receiving information and enhancing their
social lives. Thus, barriers to technology were expressed by participants to have a direct,
negative impact on their levels of independence and social engagement. **Barriers to technology**
was thematically intertwined with societal misperceptions of blindness. Self-advocacy was a
closely related theme that exerted influence over the capacity to overcome the technology-related barriers.

John spoke at length about barriers to mainstream, inclusive technology. John excels at technology and incorporates it in all aspects of his daily life. John holds a host of computer certifications and has held several jobs in IT. Despite his skills and experience, John described many frustrating encounters with barriers to technology. One common example that he shared is when technology starts off as accessible, but then changes are made to appeal to sighted people, which leave him unable to access it. John said, “Sometimes something will start out working and then somebody will just completely break it all because it looks nice.” These technology barriers greatly impact John’s independence. He stated:

If you’re going to put in a touch screen because it looks nice and it’s more efficient, or do something to your website, you should make sure that I can use it. I shouldn’t have to depend on somebody else if I go to a fast-food restaurant and now I have to use this touch screen because I can’t order from the counter. Or, if I’m at the bowling alley and I don’t have anybody with me and I can’t start my own game because somebody else has to do it because the touchscreen isn’t accessible so I can’t start my own game.

The situation becomes even further exasperating for John when the technology barriers negatively impact his ability to perform his work duties. John explained:

Even the job that I work at right now. I cannot do my full job duties because when they chose to upgrade the software, they did not bother to let blind people test it. I had been telling them for years, that we [blind people] needed to be involved in the process. They just assumed it worked because it worked before. Now, we [blind people] can’t do 70% of our job.

Carmen also discussed the frequent access issues that she encounters with new, mainstream technology. These issues present many challenges for her, as technology is central to her independence and her success as a student. She said that she reaches out to companies when
she encounters accessibility issues. She has found companies to be receptive and responsive to the accessibility concerns that she raises. Carmen feels a sense of responsibility to advocate for herself and for the blind community to reduce technology barriers that prevent their full inclusion.

Participants reported that cost and government red tape were access barriers to Assistive Technology. Three participants discussed their struggle to obtain devices or technology due to rigid, bureaucratic policies and practices. Often, the technology they were seeking was required for their independence. For example, Jayla spoke about needing a Braille writer. Despite her blindness and the apparentness of the request, Jayla had difficulty obtaining the device according to the policy standards set forth by vocational rehabilitation. Her waiting period through vocational rehabilitation was so long that she eventually ended up obtaining a second-hand Braille writer as a gift from a friend. This was technology that enabled her to be successful as a student and to immerse herself into her love for Braille, which roots Jayla in her identity.

William encountered similar access barriers to technology. His barriers had serious repercussions on his employment. William shared that he was in serious need of adaptive software and training on how to use the software so that he could keep his job as a high school teacher. William said that he could not afford to purchase the adaptive technology himself. As the high school was part of a religious organization, he was also unsuccessful at his attempts to obtain it as part of a reasonable accommodation request. William was advised by a friend to contact vocational rehabilitation. However, the wait to become eligible for services was so long that he was unable to obtain the technology that he needed for successful job retention. William lost the teaching job of three decades that he described as being “the core of myself.”
Challenges to Employment Integration

"Challenges to employment integration" emerged as the third theme of Social Exclusion. This theme describes the workplace barriers that blind individuals faced in securing and maintaining employment. "Challenges to employment integration" was identified in four narratives. These narratives included all participants who have engaged in competitive work activity. Societal misperceptions were found to be the primary factor that precluded the employment integration of participants. "Challenges to employment integration" was found to be a theme associated with a multifocal impact, affecting social, economic, and personal well-being and functioning. This theme draws emphasis to the significance of employment not only on the societal integration of people who are blind, but also on their psychosocial wellness.

Participants reported misperceptions of blindness as a major barrier to their ability to obtain, secure, and maintain competitive employment. The dominant employer misperception reported by participants was that blind people are incompetent or have reduced abilities in the workplace. David touched on how this and other misperceptions illustrate deeply held beliefs about the perceived value of blind people in society. David stated, “The misperception is that we’re worthless. There’s a reason that almost 80% of us are unemployed. Employers don’t want to bother with us.” Recent employment challenges have caused severe financial struggles for David. They have also contributed to social isolation, which has had a negative impact on his mental health and sense of self-worth.

Two participants spoke about how employers’ misperceptions of blindness are resistant to change. John shared a story about one past job that he held at a large retail organization that refused to advance him despite his competence and demonstrated leadership. John recounted:
I used to work as a door greeter at a store and they just kept saying, “Well, we don’t know what else you can do.” And they basically laid me off because they wouldn’t let me do anything else despite the fact that when I came to work, I learned my way through the store from the front to the back and you imagine how big the store is. I was able to find the time clock, I was able to clock in and out, I was even able to give a code that needed to be given for a customer who had passed out and nobody could remember it. They were on the intercom. So other than clamoring, I said, “Just say code blue!” And when they said code blue, everybody came running and they were like, “Thank you, I couldn’t remember that.” So I did all this, I passed their CBLs, everything required to work here, but then they end up letting me go because, “We don’t know what else you can do. You can’t just be a door greeter.

Anna also stated that she has had many experiences in which employers have doubted her work abilities. Unlike John, however, Anna said that she has found many employers open to shifting their views of blindness. She told one story of pursuing a job at her church. Anna said that the job was a “perfect fit” for her family’s schedule, and she was confident in her ability to effectively perform the tasks that were required. Anna was initially met with resistance from a hiring supervisor who was hesitant to offer her the job because she was blind. Anna had faced similar attitudinal barriers in the past, but said she chooses to use these encounters as opportunities to help sighted people understand that “blind people can do everything that sighted people can do, maybe just in a different way.” Anna shared:

The hiring supervisor didn’t come out and say it, but I could tell he was thinking, “Man, she can’t see. How could she do this?” Well, then finally about a week or two later, he called me and said, “Are you still interested?” I’m like, “Sure!” And so I went in there and I loaded my software for the computer and everything. And then I made adaptations where I needed. And he’s like, “Wow! You do a really nice job!” And I think he was very surprised given I am blind. He thought that if I couldn’t see that I couldn’t do anything. And I don’t think he was trying to be mean. I just think that’s the perception that people have. That if you’re blind or disabled, you can’t do things.

Anna’s ability to assert her competence, capability, and equality led her to secure the job and more fully integrate into her church community. It also made a positive impact on her employer’s view of blindness. However, not all the stories shared by participants had positive
outcomes. One such example was a story shared by William. William enjoyed a career of three decades as a teacher at a private high school. William earned a reputation as an outstanding educator and had excellent rapport with students and staff. He earned two master’s degrees in his respective field, voluntarily took on extra responsibilities to develop a music program at the school and was committed to promoting service-learning opportunities for students in the community. William stated that his blindness was never an issue at work. He was able to fulfill all his job responsibilities and, in fact, saw his blindness as an advantage to his teaching, as it provided him the opportunity to be a role model for students. William said that it was not until the last two years of his employment that he encountered severe attitudinal barriers that eventually led to workplace discrimination and job termination. William shared:

The impact of my blindness at work really kicked in a couple of years ago at the school where I was working. For the most part, my blindness doesn’t affect my ability to teach. I was always able to do everything, no problem. As far as being a teacher in the classroom, the only thing that I don’t do is read things in front of class. I give them the book and say, “read this paragraph.” That was as much accommodation that I needed to do my job. And that’s not really an accommodation.

The problem kicked in when we got a new administration on board. They didn’t want anything to do with my blindness. They said they wanted me to be able to teach exclusively on the computer. I told them that I would need time to get the technology and learn how to use it since I do everything by hand and using paper and pen. But they weren’t willing to wait, and they didn’t want to hear anything about accommodations.

It was very frustrating. It was awful. They made me feel I couldn’t do my job. And it wasn’t even that I could request additional accommodations from the school because of its association with a religious organization – they are exempt from the ADA, so I didn’t have that on my side either. They made it clear to me that they didn’t want to be flexible and they didn’t want to deal with my blindness. And to think that I’ve been a leader at the school for the past 30 years…

William’s job loss had a detrimental impact on many aspects of his life. Being single, William was able to devote himself fully to his career and students. He described his work as an
extension of himself. It rooted him “in a deep purpose” and in community with others. In losing his job, William lost what he described as “a part of myself” as well as his main source of social connection and financial self-sufficiency. Since losing his job, William has struggled to find a new and meaningful way to share his teaching talents. He has also struggled to maintain his mental health and a positive self-image. William said that he is currently trying to understand who he is as someone who is “not a teacher.” William said that this experience of job discrimination has caused him to reflect on the fact that “Much of society still can’t see beyond blindness…They see us only as people who can’t see, who can’t do things. They totally fail to see us as the brilliant people we are.”

Positive Peer Support

*Positive peer support* was a theme that emerged from an analysis of the data that was associated with the experience of social inclusion. Positive peer support was identified in all eight of the narratives. It appeared as theme within the context of interactions with other blind individuals as well as in the context of interactions with sighted people. Positive peer support was associated with several themes that enhanced the psychosocial well-being of participants. Among these included: acceptance, integration, access, pride, joy, community belonging, and personal growth. Participants’ stories evidenced positive peer support as a theme that harnessed an exceptional level of social power in their inclusion in groups, roles, and their communities. Gill (1997) theoretically attended to the influence of the disability community within the framework of another type of disability integration posited in her model. However, positive peer support will be reported on here as part of the results of the analysis of *coming to feel we belong* for its direct, countering effect on Social Exclusion.
The first type of positive peer support was that which was associated with interactions within the blind community. All eight participants had experiences to share about their associations with others who are blind, including those formed through adaptive sports, camp experiences, support groups, centers for the blind, guide dog schools, and national and state organizations for the blind. Participants spoke of the importance of these shared connections—the comfort that they feel in simply being without the need for explanation. They used words such as “free,” “normal,” and “included” to describe how they felt in each other’s presence. They described being drawn to togetherness in community with one another. Anna playfully remarked on their natural affinity for one another. “It’s like Blindar,” she said. “Us blind people find each other wherever we go.”

Participants described their friendships and connections with others who are blind to be psychosocially enriching. They helped to alleviate isolation, promoted social inclusion, and brought individuals into community with one another. For example, Mia described how meeting others who were blind during childhood was thrilling and helped her to feel less alone. Mia said:

I met my first friend who was blind back when I was in first grade. I’m like, “Oh, there are other kids like me? Cool!” And then there was a meeting of other blind kids in the same district as me. “There’s more kids like me!” And that was in elementary school. And then when I was in fifth grade, I went to a summer camp at the school for the blind. And there’s a whole school for them. Like, really? I had no idea!"

Six other participants also talked about their experiences at camps for the blind. They described camp as a highlight of growing up blind. William said amusingly, “The absolute worst threat that my mom could ever give me growing up was telling me that I couldn’t go to camp in the summer. That was enough for me to do whatever I needed to turn myself around.” David talked about the utter joy and excitement of his experiences at summer camp. David had many
fond memories of the friendships that he formed and the new experiences that he had, including his first kiss. Camp provided an opportunity for barrier-free participation and a sense of community. It was an important catalyst for exploration and growth of the self. Anna shared:

I started at camp when I was 10 and I went there until I was 18. They had programs throughout the year. And I also worked at the programs as well when I got older. So it was a huge part of my life. And being visually impaired, identifying as visually impaired. It was just a neat place that we could all go and quote-unquote, “feel normal” and have these experiences. Going swimming, horseback riding, and all that kind of stuff that you would do at regular, old camp. They had counselors who would help and they had things for baseball and all kinds of sports and swimming. They just made accommodations to do things.

Participants had vibrant stories to share of other positive experiences in which they were brought into community with others who were blind. For example, Omar talked about the excitement of participating in the Braille Olympics as a child, which was the first time that he spent a significant amount of time with other blind people. Although Omar said that he “never really noticed [his] blindness” as a child, he felt a special connection to the other blind youth at the event. Omar shared, “At the time, I just thought, ‘Oh, all these people get me. That’s cool! They’re all around my age and they’re all fun people, and good-spirited, kind-spirited. We are having a great time!’”

Mia shared stories of her involvement in highly competitive adaptive sports. One year in particular stands out for Mia as “just magic.” Mia completed her first marathon and participated in an international competition. Mia shared, “My story really blossomed from there because I lived a dream that I thought I would never live.” Through her participation in adaptive sports, Mia was not only doing what she loved, but she was expressing the essence of her true self.

John wanted to highlight the impact of the blind learning what it means to be blind from each other rather than from society. John came to understand blindness and what it meant for
him through connections that he formed with other blind individuals at a local blind center and through various blind organizations. These relationships also fostered self-awareness, self-confidence, and social integration. John shared:

When I went to the center for the blind and I actually saw other blind role models, like blind painters, blind lawyers, blind doctors, just all the people doing all this stuff and then the staff being blind. When I made a checkerboard in woodworking class…Imagine a blind person doing woodworking!

Going through all this stuff was a game changer because it showed me that, hey, you can do what you put your mind to. Blindness is not an excuse and it should not hold you back. You can do anything you put your mind to. You belong as part of society…The blind organizations was a big influence as well.

Positive peer support also emerged as a theme related to associations with sighted people. Four participants shared how these relationships and connections fostered social inclusion and positive self-growth. For example, Carmen shared that her sighted friends helped her to develop independence and self-advocacy skills. She shared, “When I was younger, it was very sweet. My sighted friends helped a lot, like going through places. They also helped me through certain things that are very difficult, like learning how to stand up for yourself. They taught me how to be assertive.” Omar also talked about the positive experiences that he had with his sighted peers at school. Omar recalled: “The few classes I would have where there wouldn’t be blind folks, those were the classes that I really felt like I was being me. And I felt like some of my sighted peers were actually willing to get to know me.” These interactions were a catalyst of social inclusion that supported Omar’s self-exploration and identity development.

William talked about the camaraderie that he has enjoyed throughout his life through his participation in a variety of bands and musical groups. William described music at the core of his identity. He stated that he has found a “profound sense of inclusion” in community with other
musicians, all of whom are sighted. Three participants talked about their experience of inclusion in their faith communities. For these individuals, faith was an integral part of their lives and their identity. Their involvement also supported self-acceptance and a sense of communal belonging. Carmen was one of these participants and wanted to share the following:

Church is a huge part of my life. I love it there – it’s where I belong. Church is what really sparked the spark in me. Growing up, I was always included at church and I was always accepted. It was a place that helped me grow in many ways. It was also a place that helped me to develop my musical talent and confidence…Spirituality helped to spark my identity. It has taught me who I really am and who I am as part of the body of Christ.

Desiring Inclusion

Desiring inclusion was the third thematic component identified in the researcher’s analysis of coming to feel we belong (Gill, 1997). Desiring inclusion describes the desire of individuals with disabilities to be included in society. This includes equal access to the same activities, opportunities, and social roles as nondisabled people. Desiring inclusion was a theme of expressed yearning. It represented the unfulfilled human need for belonging. In her articulation of coming to feel we belong, Gill (1997) used the examples of “Children with disabilities often express the desire to attend neighborhood schools ‘with everyone else’” (p. 42) and “Adults talk about equal opportunities for employment” (p. 42). Gill emphasized the function of access and equality in how people come to identify with disability. Desiring inclusion draws attention to the mediating role of oppressive beliefs, systems, and structures that keep disabled people marginalized or excluded from their communities.

Thematic evidence of desiring inclusion was identified in all eight narratives. Among participants of this sample, it was most frequently born of experiences of separateness,
segregation, or social isolation. In this way, desiring inclusion represented a crossroad between passive awareness of difference and active response to exclusion – a point that served as a vital impetus for movement toward an assertion of belonging. Two prominent themes were associated with Desiring Inclusion: desiring to be seen and resisting separation. These themes recurred across the lifespan and were found to be closely correlated with societal misperceptions and access barriers. Several themes emerged in an analysis of Desiring Inclusion, including social exclusion, ostracization, stigmatization, invisibility, social isolation, and striving for inclusion. These findings fit particularly well within Gill’s model because they attend to influences of the external, social environment on how people with disabilities come to see themselves and their place in society. Table 6 contains a summary of the findings.

Desiring to be Seen

Desiring to be seen was identified as a theme of Desiring Inclusion in five of the life stories. This theme describes the desire of people who are blind to be visible in society—to be seen, known, and understood as unique individuals and valuable members of their communities. Desiring to be seen was a recurring theme that was identified across several domains of the life story. It took many forms and emotional tones. At times, participants experienced it as a subtle longing that was deeply felt but left unspoken or disguised by negative emotions such as loneliness and despair. Other times, it took the form of a productive exchange between the sighted and the blind that led a greater level of understanding and access. Still, other times, it was experienced as a struggle expressed through frustration or anger—an outcry in response to misperceptions and barriers that attempted to undermine, invalidate, or erase their existence.
Table 6

Summary of Results from an Analysis of Desiring Inclusion

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<th>Thematic Component of coming to feel we belong</th>
<th>Desiring Inclusion</th>
<th>Description of theme: Individuals with disabilities desire to be included in society and to have access to all aspects of community life.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1</strong></td>
<td><strong>Desiring to be Seen</strong></td>
<td>Describes the desire of people who are blind to be visible in society both to be regarded as valued members of their communities and to have their access needs met.</td>
</tr>
<tr>
<td><strong>Narrative Frequency</strong></td>
<td><strong>Related Subthemes</strong></td>
<td><strong>Life Story Domains</strong></td>
</tr>
<tr>
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<td>Invisibility</td>
<td>Early Life Experiences</td>
</tr>
<tr>
<td></td>
<td>Blindness Across the Spectrum</td>
<td>Work and Education</td>
</tr>
<tr>
<td></td>
<td>Social Exclusion</td>
<td>Relationships and Social Factors</td>
</tr>
<tr>
<td></td>
<td>Societal Misperceptions</td>
<td>Beliefs About Disability</td>
</tr>
<tr>
<td></td>
<td>Awareness Education</td>
<td>Disability Community</td>
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<tr>
<td></td>
<td>Social Isolation</td>
<td></td>
</tr>
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<td></td>
<td>Access Barriers to Inclusion</td>
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| **Theme 2** | **Resisting Separateness** | Describes a person’s active resistance to the societal beliefs or behaviors that result in their segregation or exclusion. |
| **Narrative Frequency** | **Related Subthemes** | **Life Story Domains** |
| n = 3 | Segregation | Early Life Experiences |
| | Social isolation | Work and Education |
| | Stigmatization | Relationships and Social Factors |
| | Societal Misperceptions | Beliefs About Disability |
| | Striving for Inclusion | Disability Community |
| | Ostracization | |
| | Connection with Blind Peers | |

Mia’s story illustrated desiring to be seen as a theme that evolved across many life stages. It was first made evident in childhood when Mia struggled with loneliness and indistinguishable feelings of differentness. She ached to be seen in her emotional pain, and she longed for connection with friends who could respond in support to her need for inclusion and belonging. Mia’s struggle was further amplified in adolescence due to the access barriers that she faced at
school. Despite what Mia described as an ongoing “fight” to obtain appropriate accommodations, her access needs were most often left unheard or unmet. Here, *desiring to be seen* was thematically articulated as Mia’s response to being overlooked, invalidated, or misunderstood by the very people who had the responsibility to ensure her inclusion.

As Mia entered adulthood, *desiring to be seen* was expressed through feelings of invisibility as a person with low vision. Mia said that being in the “gray area” of blindness, as she considers herself to be, conflicts with society’s misunderstanding of blindness as only total vision loss. This lack of understanding has created frustrating barriers in her striving for inclusion. Mia shared:

I think that the media portrays blindness in such a way that it doesn’t leave room for people with low vision. And I think that’s a huge problem because the majority of us have low vision or a varying degree of blindness. If someone sees someone who looks like they cannot see, like their hand is trailing the wall, then people respond. But this is where I have a problem. People don’t see me. I’m in the gray area. I struggle to express exactly what I need in terms of accommodations because people still see blindness as black and white, even if it’s across a spectrum.

I just wish people understood that there’s a difference between low vision and total blindness. I find myself needing to repeat myself over and over again. It’s exhausting. It takes a lot of energy. People ask, “Why do you have your dog? You don’t look blind. What’s wrong with you?” I respond, “I’m not training my dog. He’s my dog. I can’t see very well.” Definitely zaps your energy, especially to repeat yourself.

Mia has responded to the need for an increase in the visibility of people with low vision by turning to social media as an educational outlet. Mia said that she has created content to connect with others and help inform them on blindness issues. She hopes to bridge the gap between the blind and sighted worlds and express herself in such a way that she can be seen as her authentic self.
Like Mia, desiring to be seen emerged around feelings of invisibility for William. He said that growing up with a mom who had a disability helped him to see himself from an early age as “whole and complete, blindness and all.” William shared that he felt “seen, heard, and understood as a blind child,” much in part because of the role that his mom played in ensuring that his access needs were met and that he had opportunities to interact with other blind children. William said that he noticed a marked shift in feeling seen in young adulthood when he forged into the world and for the first time felt invisible to sighted people in society. William explained:

After college, when I kind of was released into the real world, that’s when I really started to notice that society doesn’t see blind people. I think that I didn’t notice it as much when I was younger because the support was all coming my way. Even though I’ve had plenty of terrible teachers and experiences, there were always other people who were coming to help or who wanted to help. They saw me as blind and knew and cared enough to approach me if I needed help or whatever.

But once I left college, it was like no one wanted anything to do with me. I mean I had good buddies from my band and friends and stuff, but in terms of the real world, yeah, they made it clear that we are a bother in society.

I’ll tell you this. I remember this. Well, of course I take public transportation to get around and I’m used to jumping on and off buses and trains and finding my way and everything. But one time I was on my way to a job interview, and it was a new part of the city and I had no clue where I was at. I kind of freaked out because I was in a hurry and I needed someone to tell me which way to a certain street. I had my cane and everything, but that was the first time that I couldn’t catch anybody’s attention to show me the way. People were zipping by. Nobody seemed to notice me there with the cane with I am sure a frantic look on my face. I kept saying, “Excuse me…” but it was like nobody even heard. It was pretty terrible.

But, yes, much of society doesn’t see blind people even if we are right in their faces and even though most of us are trained growing up to be helpers in society. I learned from that experience. I learned that I really have to depend on myself because society doesn’t really see us.

Several life stories highlighted desiring to be seen as thematically interrelated with access barriers in the social environment. Five participants talked about how blind people are not included in the design of products and processes available to the public. For example, Jayla
mentioned her difficulty with using kitchen appliances and explained the very simple measures that companies could take to incorporate tactile indicators. Carmen talked about her struggle to obtain Braille menus at restaurants. Even for those restaurants that do have Braille menus available, she said that most businesses are not aware that they have them, or where they are located when requested. John discussed his frustration with ongoing barriers to technology, especially those that are avoidable or have an easy fix. Participants shared that these oversights and barriers cause them to internalize feelings of “frustration,” “despondence,” and “unworthiness” that push them even farther to the fringes of society. Their collective message to others is that blind people exist, they want to be seen, and they desire, like everyone, to be included in their communities.

Resisting Separateness

*Resisting separateness* was a theme of Desiring Inclusion in three narratives. This theme describes a person’s active resistance to the societal beliefs or behaviors that result in their segregation or exclusion. For participants in this sample, resisting separateness was emotionally internalized as adamant disagreement with, or refusal to accept, the exclusion and injustices that they faced. It was experienced by participants as a feeling of unsettledness—an internal stirring that moved them to expressively reject societal misconceptions and ill-prescribed methods that kept them apart from others. Resisting separateness was found to be a powerful precursor to the claiming of, or fighting for, disability rights. It thematically appeared as a teetering point between emotional saturation and emotional charge – a place between passive yearning for inclusion and action-oriented response. This theme draws attention to the vital impact of self-
advocacy and self-empowerment in growth toward an assertion of belonging, which Gill (1997) identified as central to disability identity development.

Omar’s narrative provided several illustrations of resisting separateness. It appeared most prominently as a theme of adolescence. Omar’s life story was filled with thematic examples of Desiring Inclusion. He was raised in a family that valued connection and community, and this instilled in him an understanding of societal integration as a natural extension of himself. Omar attended public schools growing up but had the unique opportunity to attend a special program for students with visual impairments during his middle school and high school years. Omar described his first few years in the program as a great, his feelings changed when he started to feel excluded from peer groups and the broader school community. Omar shared:

It was my 10th grade year that I started to say enough is enough. I started to feel this way in my 9th grade year, but it really hit in my 10th grade year. I was like, ‘What is this? You’re making a bubble for us where it’s just a whole bunch of blind people in our own little bubbles. And we don’t get much of an opportunity to interact with our sighted peers. I know that we technically had the ability to go make sighted friends. Nothing was stopping us, but there were only so many hours in the day…and when it came to socializing time, whether it was study hall or lunch, it was all done with our blind peers. It was kind of an unspoken bubble.

At first, it was social inclusion. I had fun hanging out with these blind people. Then it sort of became social exclusion. I don’t know if it was the teenage hormones or my rebel nature sinking in, but I was like, ‘No, I don’t want this. I want to be able to go chat with my sighted friends.”

This experience of exclusion was in direct opposition to Omar’s desire for inclusion. It was further compounded by feelings of stigmatization. Omar said that having extra support from Teachers of the Visually Impaired (TVIs) made him feel socially ostracized, explaining that, “Everyone saw me as the blind kid.” He resented the ways in which he was treated differently from his peers and made to feel like “a helpless blind kid.” Omar explained:
They [TVIs] would always come with me. And at the time, I just felt like this extra attachment, like I needed someone to coddle me, to accompany me to class to make sure I’m typing my note the right way while all the other sighted student are enjoying doing their thing. If they wrote notes, they wrote notes. If they feel asleep in class, that’s on them…I think my individuality was being suppressed.

Despite the emotional impact of this stigmatizing experience, Omar remained grounded in a positive self-view that resisted exclusion and embraced empowerment. Although it was a complicated endeavor, Omar was successful in advocating for a transfer out of the special program and into his local high school. There he found the inclusion and connection with his peers that was at the core of his desire and who he was.

John’s narrative also contained evidence of resisting separateness. This theme was intertwined throughout John’s journey in his pursuit of his vocational goals. This journey took root in young adulthood when John was forced to confront the possibility of living in a group home. The fear of segregation thrust him into an examination of who he was and who he wanted to become. Growing up blind, John was keenly aware of the attitudinal barriers that he faced. However, John came to a deeper awareness of the need to actively resist stigma and stereotypes of blindness in order to self-direct the course of his own life—a life in which he would discover his talents, maximize his abilities, and fully immerse into society.

Around the time when John was developing and planning his goals for the future, he started to build connections with members of blindness organizations and the blind community. John described this as a life-enhancing experience, as he, for the first time, was surrounded by people who actively resisted stereotypes of blindness and pushed beyond the barriers and boundaries that were placed on them by society. In witnessing their independence and success, John’s perception of blindness shifted into alignment with a vision of endless potential. As
John’s self-awareness and self-determination grew, so did his ambition to strive for vocational and personal success. John pursued his goals by attending college and several vocational programs. Although his path was fraught with barriers and setbacks, he persevered. John said that he was not only determined to achieve excellence, but he was determined to change the way the world saw blindness. He remained steadfast in his belief that “blindness is not an excuse and it should not hold you back.”

John went on to earn a college degree and several professional certifications. He also gained recognition as the first blind graduate of a prestigious vocational school. In addition to his day jobs, John successfully carved a path into media work. He said that he uses his work as a platform to educate, inspire, and motivate others on their own journey to achieve their dreams. It is work that captures the thematic essence of resisting separateness. John wanted to share the following message in his life story:

Just because you fail doesn’t mean that you can’t do it. You just need a different path at what you’re doing. If you have something in mind, a dream or something you want to try to go for, don’t let self-doubt, fear, or criticism from others stop you. Go ahead and shoot your shot. If you believe it, you can achieve it.

**Asserting Rights**

*Asserting rights* was the fourth thematic component identified in the researcher’s analysis of *coming to feel we belong* (Gill, 1997). This thematic component describes an exercising of one’s rights to access and equality in society. It is demonstrative of an individual’s active response to disability-related barriers, discrimination, and other social disparities that they face as members of a marginalized group. Asserting rights is a theme of self-affirmation. It reflects a person’s internalized sense of self-worth, value, and confidence that moves them to claim their
rights to active engagement and equal status in society. This thematic component draws emphasis to the history of resistance and resilience of the disability community that has played a vital role in securing rights for people with disabilities. Gill highlighted these rights and the role of the disability community in the development of an assertion of belonging. Gill stated:

> It took some particularly hardy souls among us to resist our programming sufficiently to initiate the disability rights movement. Instead of hoping for a cure to restore our social value, we could assert our rights to the mainstream in spite of our impairments. More recently, as exemplified by the Americans with Disabilities Act, we have asserted the right to be considered equal in value to anyone else, not in spite of, but with our disabilities.” (p. 42)

Asserting rights was a recurring theme that was identified in all eight narratives. It was found across several domains of the life story and associated with gaining equal access to education (n = 4), employment (n = 4), technology (n = 6), and barrier-free participation in the community (n = 8). Although all eight individuals in the sample were knowledgeable about their rights under the ADA, participants supported their claims for equal rights based on their competence (n = 5), capacity for independence (n = 8), contribution of talent and skills (n = 5), and the value of blind people to their communities (n = 5) more frequently than directly based on the ADA (n = 2). This finding suggested that individuals tapped into internal resources and characteristics rather than relying on external sources of support (e.g., the ADA) to assert their right to integration in society.

Results of the analysis pointed to two major themes associated with Asserting Rights: *effective self-advocacy* and *collective empowerment*. Although these themes were at times interrelated, effective self-advocacy primarily encapsulated an assertion of rights that was initiated on an individual level whereas collective empowerment involved an assertion of rights that was intended to generate broader implications for the blind community at large. Related
themes included: striving for independence, disability pride, positive peer support, asserting sameness, blind mentorship, barrier-free participation, and access to inclusive technology. Narratives provided evidence that these themes were correlated with positive self-concept, positive identification with disability, and commitment to the blind community. These results provide support for a sociopolitical overtone to disability identity development within the context of societal integration. This finding merges seamlessly into Gill’s (1997) model that highlights disability rights and group identity as the thematic foci of coming to feel we belong. Table 7 contains a summary of the results.

Effective Self-Advocacy

Effective self-advocacy emerged as a theme of Asserting Rights in all eight narratives. This theme describes the ability of people who are blind to recognize their psychosocial or access needs and effectively articulate those needs with others and/or within systems in order to get them met. Effective self-advocacy was a recurring theme that was identified in several domains of the life story. It was highly situational, and therefore varied in intensity, approach, and emotional spirit. Among individuals in the sample, effective self-advocacy was associated with the goals of social inclusion (n = 8), obtaining accommodations and access (n = 8), correcting misperceptions of blindness (n = 8), preserving self-dignity (n = 2), exercising freedom of choice (n = 2), and securing rights under the ADA (n = 2). Effective self-advocacy was identified as a theme of adolescence and adulthood in all eight narratives. It was uncommon as a theme of childhood when analyzed as an advocacy process initiated by the participant (n = 2); however, a few participants (n = 3) told stories of the effective advocacy efforts made by a parent on their behalf when they were a child. Results of the analysis also suggested that there...
Table 7

Summary of Results from an Analysis of Asserting Rights

<table>
<thead>
<tr>
<th>Thematic Component of coming to feel we belong</th>
<th>Description of theme: People with disabilities claim and exercise their rights to access and equality in society</th>
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</thead>
<tbody>
<tr>
<td>Asserting Rights</td>
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</tr>
<tr>
<td>Theme 1</td>
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<td>Effective Self-Advocacy</td>
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<td></td>
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<td>Disability community</td>
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<tr>
<td>Theme 2</td>
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<tr>
<td>Collective Empowerment</td>
<td>Describes the cooperative efforts of those in the blind community to achieve shared goals of access and equality</td>
</tr>
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| Description of theme: People with disabilities claim and exercise their rights to access and equality in society |

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are several psychosocial components of effective self-advocacy that contributed to a person’s self-awareness of their access needs and their self-perceived competence in getting them met. These included emotional resilience, social support, self-knowing, communicative competence, disability pride, and self-empowerment.

Effective self-advocacy was a theme that stood out in the analysis for its high frequency occurrence. Participants’ narratives depicted it like an unending, invisible thread that kept them connected to their physical and social environments. Nearly all participants (n = 7) stated that self-advocacy is a regular and necessary part of their lives. As John stated, “I self-advocate for myself all the time. Every day, all the time.” At times, effective self-advocacy was illustrated in the narratives as a goal-oriented process. It involved awareness of a need or preference followed by active steps to achieve it. This was common when individuals needed to request, or fight for, accommodations at school or work. Other times, self-advocacy appeared as a knee-jerk response—a natural and spontaneous reaction to mitigate obstacles in their environment. For example, participants spoke of providing instructions to sighted people who wanted to help them cross the street and requesting employees at restaurants to read items from menu boards.

Effective self-advocacy was associated with varied emotions. Some participants used words, such as “frustrating,” “oppressing,” “scary, “exhausting,” and “mind-spinning” to describe the process of self-advocacy, even when it yielded their desired result. Mia talked about the need to repeat herself “over and over again” to get her basic access needs met because most sighted people are uninformed or misinformed about blindness. She said, “It’s exhausting. It takes a lot of energy.” A few participants (n = 3) expressed neutral or positive feelings associated with effective self-advocacy, describing self-advocacy as a process that was at times
“encouraging,” “relieving,” “easy” or “okay.” William spoke of self-advocacy being “totally normal” for him, saying with a chuckle, “It’s something I can do in my sleep.”

Jayla told a story from her adolescence that was a powerful illustration of effective self-advocacy. This story stood out because it involved Jayla’s need to advocate for herself for basic access needs within the family unit. Jayla was confronted with a situation in which a family member demanded that she not use her cane in public with them due to its associated stigma. Jayla said that this demand was “cruel” and sent the message that she should hide her cane, her blindness, and who she was. Jayla self-advocated for herself by refusing to comply and proudly taking her cane along.

One time, when I was back home, I had a family member tell me to leave my cane in the car. I said no. Because I can’t see through stuff and I have tunnel vision from my blindness and I’m not going to hurt myself. In the past, I didn’t use my cane except when I was at my blind school. But I don’t care what people think since being at my blind school. My school really instilled in me how important the long white cane is. It’s a source of pride for me.

Jayla’s response in this situation resembled that of a reflex. It was an immediate and unguarded reaction to a potential violation of her independence, safety, and self-dignity. She shared that it was formed by the mentorship and training that she received as a student of the school for the blind. There, Jayla was taught about the importance and value of her white cane in developing independence, mobility, and identity in blindness. Jayla said that she hopes to use her training and own life experiences to help young blind children develop pride in their white cane and always self-advocate for their right to use it.

Omar shared a story that was also a powerful illustration of effective self-advocacy. However, in contrast to Jayla’s story, Omar told of a tortuous advocacy process that required thoughtful planning, persistence efforts, and a network of support. Omar’s advocacy story
centered around his decision to transfer out of the special blind program and into his base high school. This decision was prompted by a growing sense of social exclusion and repression that Omar felt as a student in the blind program. Omar’s parents were fully supportive of his choice, as was one of his TVI mentors in the blind program. However, a school official at the base high school initially rejected Omar’s request, stating that he did not view “personal preference” as an adequate justification for a transfer. This was very upsetting to Omar, as sighted students in his district were free to transfer schools without any form of justification whatsoever.

Despite this initial denial, Omar pressed on with his advocacy efforts the next school year. This time, he enlisted the assistance of a TVI in the blind program who was supportive of his choice to select the learning environment that best suited his needs and preferences. This TVI helped Omar to strategize his advocacy approach, which included highlighting the additional courses that would be available to him at the local high school, including a culinary course that was of high interest to him. Omar refined his advocacy plan and was well-prepared to make an effective argument at the meeting. However, yet again, the school official, resisted on the basis of ill-founded concerns. Omar responded by tapping into his unique strengths as a blind person – specifically, his adaptability, strategic thinking skills, and problem-solving abilities – to level up his advocacy efforts. Omar recounted:

The school official from the base high school was going through the justification documents. He said, “See, there is construction happening in the academy hallway.” I inquisitively asked, “Okay, what is the problem with that?” He responded, “Will you be able to navigate if the lights are off in that area because we’re working on the ceiling and the roofing and it will be really dark. You won’t be able to see in front of you.” I said, “Let me tell you something, I don’t see in the first place. Whether the lights are on or not, it’s dark for me.” He said, “Okay, well would you be able to navigate if they are doing construction on different parts of the flooring?” I responded, “Do you have other hallways that enter to the same hallway? Describe the floor plan of your school.”
I made him describe the whole floorplan. I was visualizing the whole thing. I said, “So, you said there’s a hallway seat here…And you said if you go to that hallway seat you can come in through the academy hallway…But you can actually go through the kitchen. You don’t actually have to cross through the hallway. Is that right?” The school official said, “There’s a back door from the kitchen to the hallway seat.” I said, “Will the instructor allow me entrance though that back door of the kitchen?” He replied, “That’s at his discretion.” I said that I would talk to the instructor. That shouldn’t be a reason why I can’t transfer schools entering through one door or another.

Omar returned to his TVI and together they accessed their networks. They found a TVI with a connection to the instructor of the culinary class. Omar immediately called the instructor to express his interest in taking his class and to inquire about the option to use the back door of the kitchen as an accessible entrance. The instructor immediately responded with no hesitation, “Sure, I give students entry through that door all the time.” He agreed to write an email to the school official to grant Omar permission to access the back kitchen door and enroll in his class. Two days later, Omar received an email from the school official at the base high school approving his transfer request. Omar shared, “I felt relieved. I felt successful. I felt accomplished. And I felt grateful for the people who were my allies.” Omar went on to enjoy his senior year at the base high school. There, he said, “I made what I would describe as the most meaningful friendships of my life…It felt much better…It just felt right.”

Effective self-advocacy was also found to be a common theme when exploring stories that involved access in the community. Anna said simply asking for help has been an effective way to get her access needs met when she is out and about with her guide dog. Generally, she has found people to be very willing to help. Anna explained:

I’ll say, “Oh, can you point me out? Or can you help me find the restaurant?” And they’ll say, “Oh, it’s right over there to the left.” And I’ll just say I’m blind because it’s hard to explain to somebody that I can see a little bit but can’t see all of it. So, when that happens, I just say, “I’m blind. I can’t see. Where is it?” And they’ll say, “Oh, my gosh. I’m sorry!” And then they show me or I follow along or whatever.
William said that advocacy is a regular part of his work as a teacher and community service leader. He readily transfers these advocacy skills to his own personal life to enhance his inclusion and independence in the community. For example, William shared that he worked with his local town officials to have several sidewalk curb ramps in his neighborhood reconstructed to be ADA-compliant. Prior to this, the curb ramps did not contain tactile dots nor were they positioned to properly cue a blind person. William said that he was pleased to see that his town officials were responsive to the accessibility issue. He said that their action on the matter sent the message that “those of us who are blind are an important part of the community.”

William also discussed self-advocacy around the area of public transportation. William uses public transit services as his main mode of transportation. William said that most transit workers know him on a first-name basis and are familiar with his access needs. He described self-advocacy as “easy,” saying that drivers are “happy to do things, such as call out routes and stops.” William attributed this ease of access to workers’ familiarity with the ADA. He also credited his own efforts to make it a point to get to know the transit workers so that he could communicate his needs and extend his appreciation for their extra assistance.

Not all of William’s self-advocacy experiences have been positive. William shared one story from a recent experience with a ride services app in which he had to advocate for himself due to poor treatment from the driver. Like past rides, William used the app to book his appointment and enter special instructions that he was blind and would need the driver to verbally call out his name and the location of the car door upon arrival. When he received a text that his ride had arrived, William keenly listened to hear the driver call his name. After a while of not hearing anything, William became anxious and decided to walk up and down the sidewalk hoping to draw the driver’s attention to him. He still did not hear a voice, but he did hear intense
honking. William said that he did his best to identify the location of the honking along the curb and eventually bumped up against a car. William spoke something to try to communicate with the driver, at which point it was finally established that he was, in fact, at the correct car. The driver then said in a stern voice, “I’ve been waiting for you.” The driver then uttered a degrading comment about blind people under his breath that William overheard.

William said that he did his best to stay calm and maintain his composure despite feeling overcome with “frustration and total humiliation.” He entered the car, told the drive his destination, and once they had driven off, William proceeded to talk to the driver about how to properly assist a rider who is blind. He said that he was careful to keep his own emotions in check so that the driver would be receptive to what he had to say. Once he arrived safely at his destination, William followed up with a phone call to the company to inform them of the incident. The company took his complaint seriously and apologized. They assured William that they would provide direct disability etiquette training to the driver and incorporate his feedback in assessing their practices in working with customers with disabilities. William ended the story by saying:

To be honest, that incident was pretty horrible. And I have thick skin. I mean I grew up needing to have thick skin, needing to self-advocate and stand up for myself. But the truth is, I eventually got where I needed to go that day…If I knew there would be one less driver on the road who’s going to mistreat another blind person, I’d go through it again one hundred times over.

Collective Empowerment

Collective empowerment was the second theme associated with Asserting Rights. It was identified in six of the narratives. Collective empowerment describes the cooperative efforts of those in the blind community to achieve shared goals of access and equality. This theme is
centered around the unification of blind people and their work toward shared goals of inclusion, independence, and equal rights. It was a thematic finding in five of the narratives. For the participants in this sample, collective empowerment took the forms of awareness education (n = 5) and peer mentorship (n = 3). Associated themes included positive self-concept, disability pride, social resistance, connection to the blind community, and effective self-advocacy. It was found to support positive identification with blindness and social inclusion. Moreover, participants spoke of the positive impact that their education and advocacy efforts had on perceptions of blindness, which in turn, had a positive impact on their feelings of acceptance and belonging in society.

Collective empowerment brings attention to Gill’s (1997) emphasis on the role of group identity in the development of a sense of belonging. Group identity is defined as a person’s cognitive awareness of, and emotional connection to, a particular social group (Tajfel, 1978). It has served to enact the grit, endurance, and resolve of disability activists and leaders in their relentless fight for civil rights (Fleischer & Zames, 2011). Gill elaborated on group identity within the context of the striving of people with disabilities for integration within oneself and within society. She poignantly stated:

Inspired by the civil rights struggle and pride movements of other minority communities, we who have disabilities have worked to define who we are and our place in society. Perhaps more than any other minority group, however, disabled people’s identity strivings have been impeded by the nagging details of our oppression. Poverty keeps resources beyond reach. Categorization by medicine and social service systems perpetuates our separation from each other. Social values that deem disability a fate worse than death discourage us from identifying as disabled individuals or seeking the company of stigmatized peers. Nonetheless, the drive for wholeness and definition has resulted not only in organizations and public policies safeguarding our rights as citizens but also cultural efforts to celebrate our differences as valuable. (p. 41)
Collective empowerment thematically embodies the unification of the blind community in their efforts to advance the rights and status of blind people as whole, valuable, and equal members of their communities. It is supported by a spirit of solidarity and driven by a sense of empowerment. Findings from this study suggested that collective empowerment may play a vital role in strengthening a person’s identity in blindness and strengthening the blind community as a marginalized group.

Awareness education was one form of collective empowerment commonly utilized by participants in this study. Awareness education involved efforts, whether formal or informal, aimed at presenting information about blindness and living with blindness. It included participation in Q & A sessions, demonstrations of skills, tools, and technology (e.g., reading Braille, working with a guide dog, using a Braille writer), and creating artistic expressions of blindness (e.g., photos, art, social media content). Participants’ stated goals of these efforts included raising awareness of blindness, correcting misperceptions of blindness, emphasizing the commonality of blind people with others, and building connections between the blind and the sighted. Awareness education involved a conscious awareness of the potential implications of their efforts on improving the lives of those in the broader blind community. One participant spoke of his work as “helping to create a positive ripple effect to bring blind and sighted people together.”

Awareness education was a typical aspect of life as a blind person for several participants in this study. It was described as essential to smashing stereotypes and breaking down barriers for the blind community. Mia, for example, talked about the view of people with disabilities as “second class citizens” who endure society’s mentality of “us versus them.” She has turned to social media to create content that brings awareness to blindness, including differences between
low vision and total blindness. This has been effective way for her to educate others while expressing her feelings and individuality. John is committed to using his role in media work to highlight the capabilities, talents, and accomplishments of the blind community. He is committed to similar opportunities to educate and raise awareness in his daily life. John said that blindness is often a good “conversation starter” and a way to draw people into dialogue with him. He stressed the importance of an open mind in transforming perspectives of blindness. John stated, “If somebody is willing to listen and they’re open-minded, I’m willing to educate them about blindness and what blind people can do and what blindness means. So, I try to use my blindness whenever I can to try to educate people.”

Awareness education was also a way that participants promoted acceptance and celebration of blindness. David’s told stories of his work talking to classrooms and groups of children about living with blindness. David marveled at their curiosity and openness to blindness, which led them to “ask the best questions.” The children were especially thrilled by the sight of his guide dog who added a warm and delightful spirit to the experience. David joyfully recalled:

I used to do Q and A sessions for children’s groups and classrooms. I’d bring my guide dog, and if everybody behaved themselves, the prize would be that they would get to pet the dog. The younger the kids, the better the questions were. My favorite question they would ask me, for example, was “How do you eat?” And I would describe to them just [how] I would eat. And I would say that I learned how to raise up the spoon and where my mouth was and put the spoon into my mouth. I told the kids to imagine doing it with their eyes closed. That’s the best way to imagine how I do things.

David’s work opened children’s eyes to see people who are blind as “just like them.” His sharing invited them into an understanding of disability as a difference to be embraced rather than feared. Carmen’s focus on awareness education mirrored this same spirit. Carmen expressed
that blindness has been a gift in her life and it is what has allowed her to become the person who
she was meant to be. Carmen seeks to share her joy and pride in blindness with others in her
daily life encounters to teach them that “blind people can do anything than sighted people can
do. Sometimes even better.” Carmen believed that the most powerful forms of awareness
education is building shared connections with others. She talked about the importance of people
taking the time to get to know more about the blind in creating a more inclusive society.

I just wish people would take the time to meet positive blind people. To take the time to
meet them. To sit down and talk to them. They would probably find that they have many
things in common with a blind person. They would realize that we are all the same at the
core, just different in our own unique ways. That would be real teaching and real
learning. And that is what I would like to see in society.

*Peer mentorship* was the second theme associated with Asserting Rights. It was identified
in three narratives. Peer mentorship was found to draw a person closer into connection with the
blind community and more fully into connection with society. This played a significant role in
strengthening their identity in blindness and empowering them in many aspects of their lives.

William spoke in-depth about the influence of his mentor “Daniel” in shaping his views
of blindness and his views of himself. William shared that Daniel was the reason that he “had the
guts to pursue my musical dreams as a blind guy.” William was connected to Daniel by a
professor in college who recommended Daniel as an outstanding teacher of classical guitar. The
professor did not mention Daniel’s blindness, so William said that he was utterly shocked when
he arrived at Daniel’s studio door and was greeted by a music teacher who introduced himself
and then explained that he is blind. William said that, in that moment, he felt an instant
connection to him. William recounted:
It was the strangest thing, but the strangest in the most positive way possible. I still remember everything that happened at that first meeting. He said, “Hey, William, come in. I’m not sure if Prof B told you, but I’m totally blind, so why don’t you come over here and we’ll sit and talk some music.” William said in response, “Ummm, this is weird, but I’m blind too.” We were both equally shocked. Our jaws were to the floor. It was pretty unforgettable. I mean, what were the chances that my instructor would be blind? It was really cool. It was like finding a long-lost brother or something. That’s the only way I can explain it. That was it. He was my teacher over 22 years.

William said that Daniel was instrumental in his growth as a musician and as a blind man. He admired Daniel’s musicianship, his artistry, and his confidence in his own blindness. William said that most significant was how Daniel introduced him to two worlds: the musical world and the blind world. William shared that because of Daniel’s mentorship, blindness began to take on a new meaning for him. William started to feel less motivated to hide his blindness and conform to society’s standards. Instead, he felt empowered to grow into own and interact with others as his authentic self. William shared:

Yeah, it wasn’t too, too long after I started taking lessons from him [Daniel] that I noticed a shift in how I saw blindness. I spent most of my teenage and college years just doing my best to blend, you know, to act as “normal” as possible. I started to question my need to do this. I mean if I could be as cool and accomplished as Daniel, why would I, right? So, yeah, I started to feel less pressure to hide my blindness, because I would do that a lot when I could. I eventually stopped worrying about what other students and people thought when I held my paper so close to my eyes or used my cane. This was a major weight lifted off me. But the point is, I started to see my blindness as maybe a good thing – like David would say, something that made me unique as a musician and a person.

Omar also spoke being empowered and inspired by blind role models, mentors, and leaders in his life. His family was instrumental in helping him to form these connections from an early age. Omar identified two of his mentors in the blind community who had a great influence on his perceptions of blindness and his life. He first met them around the age of ten when his
family attended a convention of a blind organization. Their wonderful conversation at the convention led to a dinner together that left a lasting impression on Omar. He recalled:

And, of course, it is the Arab tradition that whenever we have a great conversation with someone, we invite them over for dinner…They graced our dinner table and they showed us different technologies. They showed us how they can scan a juice carton and know all the contents. So, it was like, “Oh, so when I go to the grocery store, I can buy stuff and know what’s actually in it.” And this was before voiceover, so technology was older. But I was still inspired, nonetheless, by the technology they were using and the conversations that we had. I was like, “Wow!” That feeling stuck with me.

Although the value of their mentorship remained with Omar, he did not continue his participation in the blind organization under the assumption that it was “just a whole bunch of old dudes,” However, Omar’s perspective on involvement in the blind organization changed when he had the opportunity to assume the role of mentor for blind children in young adulthood. One of his first opportunities involved teaching Braille to children. Omar told a story from his work with one child that awakened him to the great meaning and influence of sharing his life experiences and skills with others. He recounted:

I was teaching him Braille. I remember we were cracking jokes and he just randomly said something. He butchered the word, but said, “You inspire me.” Hearing that meant so much. It struck me. I was like, I have something to offer to the next generation. I had experiences. But let my experiences not only be mine but let them be experiences that others can build upon and use as a guide for themselves.

And that was really pivotal because then I realized that my involvement with the blind organization meant giving to other blind folks. So, I said, let me give one meeting a try. I gave one meeting a try. By the end of that meeting, I was volunteering for three responsibilities at our state convention in November. And picking up those responsibilities felt empowering because no one stopped me.

I remember two or three weeks later, I got a call from my blind mentor and he said, “You know, Omar, I remember you when you were young. You disappeared. You never came back. I knew you’d come back around eventually. I’m glad you came back when you had something to offer.”
In reflecting on this experience, Omar shared these feelings around the importance of mentorship on empowering blind people into independence and community involvement.

I felt like I had done something with my life. And it meant so much coming from one of the people who I’ve never openly articulated was one of my biggest role models. And it meant so much because I realized that’s what we have to do. We just have to put faith in others. Give others the benefit of the doubt and provide them any supports and resources if they ask for it. Not preemptively, only if they request it. And to communicate for it and advocate for it.

And another thing I learned was a true mentor is one who lets their mentee decide when they need to be mentored. And I hope that the young individuals I’m mentoring to this day can gather that from me as their mentor. And I hope I can inspire them. I hope that I can give something from my experience and hopefully gain something from their experience. Because that’s what we do in this life. We trade experiences, we trade ideas, we share dialogue. And I think that I was not able to re-experience, re-feel some of these emotions until I rehashed them out here with you today.

**Expecting Access**

*Expecting access* was the fifth and final thematic component identified in the researcher’s analysis of *coming to feel we belong* (Gill, 1997). It states that in understanding equal access as a societal responsibility, individuals with disabilities not only assert their right to inclusion but come to expect it. Expecting access represents the apex of integration into society. It underscores the dynamic interaction of advocacy, empowerment, community, independence, and pride in developing a sense of belonging that is socially experienced and psycho-emotionally internalized. Expecting access thematically expresses Gill’s last line of text in her description of *coming to feel we belong*. She stated: “We have dared to expect accommodation for our differentness. We have also dared to place the blame for ‘not fitting in’ more on the creators of restrictive environments, roles, and occupations and less on ourselves” (p. 42). Such views resist
mainstream perceptions of disability by emphasizing barriers as the result of sources external to the person and apart from their disability.

Results of this study found thematic evidence of Expecting Access in all eight narratives. It was expressed as a single theme, defined in this analysis as *access as an expression of unity and belonging*. This theme places emphasis on the role of access as an assertion of belonging. It describes views that access is a necessary means of social inclusion, appreciation for disability diversity, and the collective thriving of communities. It frames access as a societal, not personal, responsibility – as an expectation as much as a right. In this way, access as an expression of unity and belonging yields a pull to belonging rather than merely a push to integrate amidst resisting social forces (i.e., asserting rights). Thus, it was a thematic illustration of achievement of the first type of disability integration defined in Gill’s model (i.e., *coming to feel we belong*).

Access as an expression of unity and belonging was a theme of late adolescence and adulthood. For individuals in this sample, it was a theme that represented a self-expressed social ideal much more frequently than an actualized experience. Although all participants expressed personal views and values that were consistent with Expecting Access, these views and values were reciprocated by their social environments only sporadically (n = 3) or rarely (n = 5). For both frequency groups, access as an expression of unity and belonging was associated with authentic self-expression (n = 4), participation in positive social change (n = 4), and feelings of hopefulness (n = 3). These supported connections between the blind and the sighted that satisfied their desire to be seen, valued, and belong. A summary of findings is contained in Table 8.
Table 8

Summary of Results from an Analysis of Expecting Access

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<thead>
<tr>
<th>Thematic Component of <em>coming to feel we belong</em></th>
<th>Description of theme: In understanding equal access as a societal responsibility, individuals with disabilities not only assert their right to inclusion but come to expect it.</th>
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<tr>
<td>Expecting Access</td>
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<td>Theme 1</td>
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<td><strong>Access as an Expression of Unity and Belonging</strong></td>
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<tr>
<td>Describes access as a necessary means of social inclusion, appreciation for disability diversity, and the collective thriving of communities.</td>
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<tr>
<td><strong>Narrative Frequency</strong></td>
<td><strong>Related Subthemes</strong></td>
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<td>n = 8</td>
<td>Self-Acceptance</td>
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<td>Disability Pride</td>
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<td>Interconnectedness</td>
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<td>Positive Self-Image</td>
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<td>Hopefulness for the Future</td>
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<td>Social Inclusion</td>
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<td>Inclusive Technology</td>
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<td>Striving for Independence</td>
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<td>Collective Empowerment</td>
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Access as an expression of unity and belonging was a stark thematic contrast to the results from the analysis of the previous four thematic components (i.e., confronting difference, social exclusion, desiring inclusion, and asserting rights). Whereas previous themes highlighted societal attitudes and responses to blindness as the cause for various forms and levels of exclusion, access as an expression of unity and belonging focused on the potential of societal attitudes and responses to invite inclusion. Despite the idealistic nature of this theme, participants told stories that conveyed it with clarity and robustness. They emphatically spoke of access – environmental and attitudinal—as an expression of respect and compassion. Carmen said that it was “the clearest way that people can communicate that they see us, and they want us to be part
of things with them.” Some spoke about the ways that access opened opportunities for them and others – disabled and nondisabled alike. Mia, for example, referenced the tremendous benefits of Universal Design in designing accessible spaces that send the message that all are welcome.

John talked about the value of access in bringing people of diverse backgrounds together to learn from each other and to gain inspiration and strength from one another. William echoed this sentiment in sharing his deeply held belief that access is a unifying agent of society. He described it as “the epitome of inclusion…what bridges the blind and sighted worlds together.”

Access as an expression of unity and belonging was expressed throughout the life stories most frequently as a yearning, hope, or vision for society. There was a total of 31 excerpts from stories in the sample in which access as an expression of unity and belonging was found in the form of a social ideal that was expressed but not experienced. In contrast, there was a total of nine excerpts that typified it as an actualized experience. This marked difference was consistent with most stories shared by participants that illustrated the stigma, misperceptions, and barriers that they faced. Despite its low frequency occurrence, actualized experiences of access as an expression of unity and belonging were associated with highly positive emotions. Participants used words, such as “awe, “elation,” “excitement,” and “thrilling,” in recalling times in their lives when society’s efforts to ensure their inclusion matched their own visions of access. Their voices resounded feelings of hopefulness and optimism in sharing these stories.

One such story was told by Mia. An illustration of the theme is best viewed within the context of understanding her persistent struggle for access. Mia said that she spent much of her life fighting to be included and fighting to prove her worthiness in a society that viewed her as a “second-class citizen.” Mia longed to be regarded as equal, and she longed to be seen as “a person first.” She was often alone in her fight and, at times, received little support from those
around her. Mia said it was an isolating and emotionally exhausting struggle. Despite this, she persisted. Mia grounded herself with the knowledge that she was a competent, adaptable, resilient, and compassionate individual. She connected with people who were supportive of her goals. She regularly exited her own comfort zone, with her guide dog at her side, to grow in courage and independence. Mia also devoted herself to adaptive sports, which was an area where she felt that she could authentically express herself and find her joy. As Mia shared, “My story really blossomed through adaptive sports.”

At one of her highest points as an athlete, Mia earned the opportunity to participate in an international sports competition. She thoughtfully reflected on the opening ceremony. Mia described it as an incredible display of unity and a celebration of diversity. She said access for people with disabilities was made a priority. The event even included audio description for the blind, which Mia said is a rare occurrence. It was an emotionally striking experience for Mia, as it was the first time that she experienced her envisioned ideal of access and inclusion without a request, let alone without a fight. Mia shared:

> It just made me realize how much bigger the world is and how much less alone I actually am. I think what made me truly realize that was when I was at the opening ceremony. There was audio description, there was access, and it was just pride. The message overall was loving unity, no matter who you are.

This experience left a lasting impression on Mia’s mind and her heart. She said that on that day she felt visible and valued as a person with a disability. She also felt a tremendous amount of pride. “People care,” Mia said. “And we don’t have to tell them how to care.” She was inspired with a sense of hopefulness, there after placing her vision of access and inclusion somewhere along the figurative spectrum of what she believed was possible for society.
Like Mia, Carmen also expressed feelings of hopefulness when she reflected on the ways that she experiences society responding to access. One of these ways centered around advancements in technology. Most exciting to her has been that companies are designing mainstream technology with accessibility in mind. Carmen shared:

I feel hopeful about the future. I feel like with technology we are moving in the right direction. I feel like the path is going forward, not backward. And I see it only going forward toward inclusion from here. It says that society is starting to see us…Yes, there is definitely hope.

Carmen said that these improvements have made it possible for her to enjoy the same level of connection and access to the world as people with sight. This is especially important to her as a student and young adult who is navigating a sighted world that demands technological competence. Carmen also said that these improvements help to remove a burden off disabled people by focusing on access as a universal need of all people.

Whereas some participants stressed physical or environmental aspects in access as an expression of unity and belonging, others focused on attitudinal ones. William described access as a coin with two sides in which physical access occupied one side and society’s perceptions of blindness occupied the other. “One cannot exist without the other,” he said.

David’s story highlighted the aspect of attitudinal access. David’s story centered around his success in his professional career—a career that he described as a fundamental aspect of his identity and how he best expressed himself. David’s journey toward success did not come without a struggle, however. In the beginning, he faced many barriers. David said that people were resistant to offer him a chance. He stated, “They didn’t want to work with a blind guy.” Eventually, through persistent effort, David connected with someone in his field who was
unphased by his blindness. Instead, he saw David for his passion, talent, and potential. He agreed to give David an opportunity to work with him. Not long after, their collaboration took off. They learned to accommodate one another to bring out each other’s strengths. Their remarkable synergy led to incredible opportunities on a national level.

At one of the highest points of his career, David’s skills earned him considerable notoriety in his field. He remembered the ways in which he was known and celebrated as a professional who achieved great things with blindness, not despite blindness. Blindness, which at times had been a source of societal exclusion, became the very feature that drew David closer into community with those whom he felt he truly belonged. David reimagined his emotional experience around this time, describing it as, “Excitement like you wouldn’t believe!” He reflected with gratitude and joy on the extraordinary dream that he both imagined and lived.

Anna added additional perspective into attitudinal access as a component of access as an expression of unity and belonging. Anna stated the importance of self. She spoke about how her own comfort and openness about blindness has had a positive influence on how others respond to her blindness and her access needs. For example, Anna talked about her decision to bring her guide dog to job interviews, which is not what many blind people who she knows do out of fear of discrimination. Anna, however, says with joy and pride, “This is me!” Anna was hired on-the-spot at her most recent job interview in which she took her guide dog along. It has been experiences such as this that have boosted her self-confidence as a visually impaired woman and her confidence in society’s capacity to understand and respond to the access needs of people with disabilities.

Access as an expression of unity and belonging was also illustrative of collaborative efforts to increasing access. Participants spoke about the ways they have chosen to do their part
to create a more inclusive society. Jayla, for example, is dedicated to using her role as a Braille teacher to inspire a new generation of blind children. Jayla was brought to tears upon reflecting on the ways that she will help blind children grow in confidence, independence, and pride. She said that she is driven by her vision of inclusion and equality. “We’re all human beings. We breathe the same air. We all belong here,” Jayla said. Similarly, William uses his role in community service work to bring awareness to, and address, the needs of the marginalized and underserved in his community. William said that those he works with have learned, through exposure and experience, how to communicate with, assist, and ensure the rights of those who have disabilities. “People just need to be taught how to best help disabled people.” Once they know how, they do. They really want to learn and that’s what’s most important.”

Omar introduced an element of universality to access, expressing *access as an expression of unity and belonging* as a theme of shared responsibility among all those in society. Omar stated that access is a concept that is not exclusively tied to the experience of disability. According to his view, access is a concept that is tied to the experience of community—of people taking care of one another and accommodating for the differences that are inherent to the human experience. Omar shared:

> We’re all disabled in our own ways. We may not have a physical or apparent disability. We may not have something that could be diagnosed medically, but there’s something we always feel we need to compensate for psychologically. And whether that’s warranted or not, there’s always that need for self-compensation. I think that should remind us all that we should do the best to accommodate each other and accommodate each other’s needs because we’re all compensating for something.

William echoed Omar’s sentiments in stating, “Access is a social responsibility. It’s everyone’s responsibility. Access is for the benefit of everyone. Meeting each other’s needs is what makes
us stronger as a society. We can’t expect to collectively thrive if we leave anyone behind or anyone out.”

Results of Analysis of Disability Identity

The disability identities of participants were directly explored under two domains of the Life Story Interview (i.e., Beliefs About Disability and Disability Community). Participants spoke about their views of blindness and how they saw themselves as blind individuals. Each had their own unique culture, social environment, life circumstances, and perceptions of blindness through which their disability identity was formed. The results of this analysis indicated that all eight participants had affirming disability identities. They regarded blindness as an important and integral aspect of who they are and how they express themselves in the world. Moreover, all self-described positive associations with the blind community and/or the larger disability community. These findings were based on participants’ responses to items that directly explored disability identity (e.g., How important is blindness to who you are?; What does the word blindness mean to you?; If you were asked to provide five words or short phrases to answer the question, “Who am I?” what would they be?) and the stories they told that either directly or indirectly expressed such data. The disability identities of individuals in this sample were expressed as either one of two themes: blindness as natural (n = 5) or blindness as strength (n = 3). Several psychosocial factors and experiences were found to play a mediating role in the development of their disability identity. These will be reported under their respective theme identified in this section. Table 9 contains a summary of the results.
### Summary of Results from an Analysis of Disability Identity

#### Themes of Disability Identity

**Theme 1**  
**Blindness as Natural**

Describes an identity in which blindness is viewed as an inherently neutral characteristic

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<thead>
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<th>Narrative Frequency</th>
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**Theme 2**  
**Blindness as Strength**

Describes an identity in which blindness is viewed as a desirable attribute that is a source of strength and pride

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<tr>
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</table>
Blindness as Natural

Disability Identity was expressed as the theme *blindness as natural* in five narratives (i.e., William, John, David, Anna, and Omar). Participants in this thematic group viewed blindness as an inherently neutral trait. They described it as a characteristic that is similar with other identifying features of a person, such as their ethnicity, height, or occupation. As such, their experiences with blindness were heavily influenced by the physical and attitudinal environments in which they functioned. Moreover, participants in this thematic group reported consistent views of disability as natural across the lifespan. None indicated a sense of loss, “missing” sight, or negative self-views due to being blind. On the contrary, all five expressed positive identification with blindness, using words and phrases, such as “acceptance,” “normal,” and “feels exactly right,” and “simply a part of me” to describe their feelings about being blind. As William stated, “For me, it is just a matter of being me. I was born this way. I have always been this way. Blindness might be something that sets me apart from others, but for me, it feels exactly right.”

Blindness as Natural was found to be associated with two themes: facilitating self-growth and authentic self-expression. Omar’s story of identity development illustrated these themes. Omar stated that he has multiple facets to his identity, describing himself as an “independent, self-empowered, self-driven, and motivated Palestinian American, Middle East food connoisseur.” Omar said that he intentionally omitted blindness from this description, not because blindness is not an integral aspect of who he is, but because blindness is driving his growth not defining it. Omar talked about the role of his parents and culture in establishing the foundation for his identity development. He shared:

I was born into a family of very accepting, but also very determined folks. My parents had their own backstory and they always reminded us of it...They had to work hard...My parents always reminded me that if they can do it, anyone can do it. And, so it was really drilled into me from when I was a kid that I make my own destiny and I decide how...
others are going to perceive me by establishing my own self-perception and creating my own identity.

I fall back onto my Arab roots to remind me of that and striking that balance between individualism and service to community is just so beautiful. I think those are the core elements to forming who I am and establishing a base upon which I move and motivate myself.

William’s story also provided an illustrative example. William spoke in gratitude about the ways that blindness has paved the way to authentic living and authentic self-expression. William said his identity in blindness was uniquely shaped by being raised by a mother who had a physical disability. He stated that much of his learning in life occurred through the lens of disability. Williams described disability as “totally normal in my house growing up.” In fact, he did not become fully aware that his mom was any different from other moms until around the age of seven when his friends at school asked him, “What’s wrong with your mom?” William’s mom was also a director of a camp for children with disabilities, so he had early exposure to disabled peers. William said, “I didn’t associate disability or blindness with anything negative at all. My mom was the most incredible person I knew, so I knew that, if anything, blindness meant something positive for my life.” He talked about blindness paving the way to music and teaching, both of which are at the core of his identity and how he expresses himself. William shared:

If I wasn’t blind, I probably wouldn’t be a musician. That’s how I look at it. I’m grateful to be blind because it’s brought me to my music and it is what has allowed me to connect to my students on a deeper level. I have to use this experience to help others somehow. So I absolutely wouldn’t trade my disability for anything. Everything I have ever wanted and ever wanted to do is because … I am blind.

Like William, Anna also spoke of the positive influence of her family on her disability identity. Anna said that she has always embraced blindness as simply part of who she is. She
credited this to being raised in a family that provided the structure and support to help her grow in self-worth, self-confidence, and independence. “I always knew that with some modifications or adaptations, I could do anything,” she said. Anna said that her parents adamantly rejected the notion that blindness was in any way tragic even when that was the message that they received from medical professionals. Her parents were strong advocates for her inclusion throughout her school years and also worked to ensure that Anna had opportunities to attend blind camp and interact with other blind youth. Together, their attitudes and efforts formed a solid foundation from which Anna formed positive identification with blindness. Now as a wife, mother, and school professional, Anna teaches her children and students, through her example, about the importance of integration, the value of disability diversity, and the endless potential of people with disabilities.

Two participants in the Blindness as Natural thematic group addressed the impact of stigma, negative stereotypes, and misperception of blindness on their disability identity. They spoke about the challenge that it is to uphold their positive self-views when they clash with society’s overtly negative views of blind people. John, for example, who stated that his blindness makes him “no different than others,” struggles to be perceived by society in the same way that he perceives himself. John described himself as an independent, intelligent, and successful blind man and father. His identity remains rooted in a strong sense of self and continually nourished by his meaningful connection to the blind community. Still, John said that he must work unduly hard to prove to others the identity that he holds true for himself. He stated that society’s perceptions of blind people as incompetent and dependent clash with who he is and how he expresses himself in the world. Still, he said, “I wouldn’t change being blind because I wouldn’t want to change who I am.”
David also spoke about the impact of attitudinal barriers on his identity. David described blindness as “normal” and what makes him whole and complete. “It’s the only life I’ve ever known,” he said. David thrived, both socially and professionally, when his blindness was appreciated by others as an integral and important aspect of who he is. This is best exemplified by the highlights of David’s career – a time when his blindness was celebrated by those who came to know him as the talent that he has established to be. David said that during this time, he was empowered to be “exactly who I am.” This contrasts with times when he has encountered unemployment struggles and other blindness-related challenges that have resulted in significant social isolation. David said that society’s devaluation of blind people is the greatest barrier to maintaining and expressing pride in a blind identity. David wishes for the world to know that “We [blind people] are perfectly normal people other than we can’t see.”

**Blindness as Strength**

*Blindness as strength* emerged as a theme of the disability identities of three individuals in this sample (i.e., Carmen, Jayla, and Mia). These participants not only described blindness as an inherent part of themselves, but as a valued and desirable aspect of who they are. To them, blindness was a source of strength and pride. One participant in this thematic group reported consistently positive views of blindness since childhood. The remaining two participants described significant changes in their perceptions of blindness over time. Positive social supports and connection with the blind community were found to be the primary mediating factors in the development of disability identity expressed as *blindness as strength*.

Carmen spoke in descriptive detail about her identity in blindness. At one point, she was moved to tears upon reflecting on what blindness means to her. Carmen shared, “Blindness is
who I am and I love it…I’m crying happiness…Blindness is a beautiful part of who I am.”

Carmen stated she has had consistently positive views of blindness since childhood. She said that her family, friends, and church have helped to instill in her a strong sense of self-worth, pride, and joy in blindness. Carmen shared, “They have always loved me as I am, and they have made me feel proud to be blind.” Carmen also talked about the ways that blindness is her “strength in life.” She said that it enhances her imagination, her appreciation for music, and her ability to experience deeper connections with others. Carmen shared, “Because I don’t have sight, I don’t have the distraction of sight. This makes it possible for me to see inside of other people and get to know them on a deep level. I’m not focused on the visual aspects of a person, so I am able to get to know them for who they truly are.”

Like Carmen, Jayla’s identity is firmly rooted in blindness. Jayla talked about blindness being the “essence” of who she is. For her, it is a source of empowerment, pride, and personal strength. At one point in telling her story, Jayla brought up a theoretical cure for her blindness, to which she said, “I don’t want to change who I am. It’s funny. They are working for a cure, but I don’t want the cure because I feel like if I did get the cure, then I wouldn’t be Jayla anymore.”

As Jayla previously shared, her experiences with blindness have not always been positive. It was not until she started attending the residential state school for blind at the age of 10 that she first experienced feelings of acceptance and inclusion. Jayla talked about the importance of being surrounded by others who were blind in an environment that was designed to support her independence and growth as a whole person. Jayla shared:

I really discovered myself as a visually impaired person at the blind school. Being there was the first time that I felt that it’s okay to be blind – that I’m not the only blind one in the world. I felt like I was accepted and I could share my visual impairment story and maybe there are some that are similar to me.
The task of exploring her blindness increased in adolescence. Jayla shared a story about writing a report about her vision conditions for an English class, which she said was the first time that she had access to detailed information about her vision conditions. Jayla said the process of research and writing about her blindness was empowering. Through this process, she began to develop a deeper understanding of blindness and its defining role in her life. “That’s when I really started learning about my blindness and discovering myself as a blind person,” Jayla said. Her connection with her blind peers was especially crucial during this time. It was in community with other blind people that Jayla said that she was able to explore who she was without question or doubt of her capacity or potential. Jayla even started to learn Braille at the age of 17, which quickly became one of her greatest passions in life and one of her great joys of blindness.

In reflecting on her disability identity and dreams for the future, Jayla expressed gratitude for blindness—for how it has allowed her to become the person who she was meant to be and for what it has taught her about humility and equality. She is committed to using her life experiences to empower blind children to find their own meaning and joy in blindness. “I want to give back to people who have helped me and to my blind community,” Jayla said. “I especially want to help the blind community…I am really excited about what God has in store for me.”

Mia was the third participant whose identity was expressed as blindness as strength. Her story of identity development was unique, as it involved dual integration of both disability and culture and longitudinal growth in perceptions of blindness over time. As previously shared, Mia was raised in a home and community that was heavily influenced by her Korean culture. Mia said that she often felt torn between two worlds. “If I was home, I was Korean. And if I had to step outside of my home, I had to be anything but Korean just to fit in,” she said. This struggle to fit in also applied to being blind. Mia was bullied, ostracized, and frequently left out of
opportunities and activities due to a lack of access, both environmental and attitudinal. This resulted in painful feelings, including self-consciousness, loneliness, and confusion, which created barriers to positive identification with blindness. These feelings were then intensified in high school when Mia began to explore who she was on personal, cultural, and social levels.

Late adolescence and early adulthood marked a turning point in Mia’s identity development. She stated that her perception of blindness began to shift when she became involved in adaptive sports. Mia said that through adaptive sports she was able to explore who she was and authentically express herself as the person she wanted to be. Her self-awareness, self-confidence, and independence grew, as did her understanding of what blindness meant to her. Adaptive sports also provided an avenue through which Mia was able to build connections and friendships with others who have disabilities. The feelings of acceptance and belonging that she experienced as being part of the disability community fostered in her a growing sense of wholeness and pride in being blind. Around this same time, Mia also started to integrate herself more into Asian American communities. This not only helped her to develop her identity in her Korean culture, but it was an opportunity to educate them on blindness. “They didn’t have much understanding of the disability community.” Through these immersive experiences and the support of her communities, Mia began to discover and define her own unique identity that was integrated in both her Asian culture and her blindness.

Upon reflecting on how her disability identity evolved, Mia shared: “I think that so much of my life has been spent wasting my time trying to blend in that I didn’t learn how to be who I want to be. It’s harmful. It’s harmful because I lost so much time trying to fit in and not be who I was wanting to be.” Now, as a young adult, Mia appreciates blindness as a strength for how it has been a facilitator of self-growth. She shared that blindness has transformed her from being a
realist to an optimist; instilled in her a passion for equality and justice; and, taught her the skills to advocate for access and inclusion, both for herself and others. Most important to Mia, blindness has become a source of her expansive compassion for others. Mia expressed, “My compassion has become more and more encompassing because I struggled so much as a kid.”

Summary of Results of Thematic Analysis

This study investigated the first type of disability integration (i.e., coming to feel we belong) defined in Gill’s model (1997) in a sample of eight adults with congenital blindness. The researcher used a Life Story Interview methodological approach to explore the process and extent by which these individuals came to assert their right to belonging in society. Results indicated that all eight narratives contained themes that aligned with the five thematic components that were identified by the researcher in her analysis of coming to feel we belong. These results are consistent with the finding that all participants had affirming disability identities and expressed a sense of belonging in society.

There were three results that stood out in the analysis. First, seven narratives contained themes that directly included all five thematic components. The remaining narrative did not include a theme aligned with the description of the first thematic component (i.e., confronting difference). It did, however, contain themes that aligned with all others. Second, consistent across all eight narratives, the second thematic component of coming to feel we belong (i.e., social exclusion) contained two or more themes that directly aligned with its description and one theme (i.e., positive peer support) that was outside its description. This finding points to the significance of positive peer support in developing positive self-views of blindness and feelings of belonging in society. Third, all eight narratives contained data that thematically illustrated the
last component (i.e., expecting access) as a single theme (i.e., access as an expression of unity and belonging). This theme signified a unified expectation of access that gave voice to their collective call for inclusion in society. Moreover, according to the researcher’s analysis, satisfaction of expecting access represented achievement of the first type of disability integration defined in Gill’s (1997) model. This analysis found that all eight participants achieved this highest-level thematic component. A pictorial summary of these results is found in Table 10.

Psychosocial Factors that Influenced Disability Identity

Several psychosocial factors and experiences were found to exert influence over a person’s perception of blindness and their disability identity development. The most prominent and frequently cited factors in this study’s analysis included: (a) family response to blindness, (b) societal misperceptions of blindness, (c) educational support, (d) access barriers, (e) disability community, and (f) other blindness-related factors. A descriptive report of the psychosocial factors associated with each thematic component was provided earlier in this chapter. This section will summarize these results and identify thematic patterns of interest that were noted among participants in the sample.

Family Response to Blindness

*Family response* was found to play a significant role in a person’s early perceptions of blindness. For individuals in this study, it was a factor that was most evident in stories of childhood. A family’s response to blindness involved the influence of several variables, including their culture, beliefs about disability, parenting style, and own experiences. In general, this analysis found that participants who were raised in a family that embraced blindness and
Table 10

Alignment of Themes Contained in Life Story Narratives with Thematic Components

<table>
<thead>
<tr>
<th>Narrative Source</th>
<th>Confronting Difference</th>
<th>Social Exclusion</th>
<th>Desiring Inclusion</th>
<th>Asserting Rights</th>
<th>Expecting Access</th>
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<td>▲</td>
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<tr>
<td>Anna</td>
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<td>Participant B</td>
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<td>▲ X</td>
<td>▲</td>
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<tr>
<td>Carmen</td>
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<td>X: Positive Peer Support (sighted peers)</td>
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<td></td>
<td></td>
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<tr>
<td>Participant C</td>
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<td>▲ X</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
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<tr>
<td>David</td>
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<td>X: Positive Peer Support (blind peers)</td>
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<td></td>
<td></td>
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<tr>
<td>Participant D</td>
<td>▲</td>
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<td>▲</td>
<td>▲</td>
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<tr>
<td>Jayla</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Participant E</td>
<td>▲</td>
<td>▲ X</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td>John</td>
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<td>X: Positive Peers Support (blind community)</td>
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<td></td>
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<tr>
<td>Participant F</td>
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<td>▲ X</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td>Mia</td>
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<td>X: Positive Peer Support (blind peers &amp; blind community)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant G</td>
<td>X</td>
<td>▲ X</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td>Omar</td>
<td>X: Awakening to Self-Potential</td>
<td>X: Positive Peer Support (blind peers &amp; sighted peers)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant H</td>
<td>▲</td>
<td>▲ X</td>
<td>▲</td>
<td>▲</td>
<td>▲</td>
</tr>
<tr>
<td>William</td>
<td></td>
<td>X: Positive Peer Support (blind peers &amp; sighted peers)</td>
<td></td>
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</tbody>
</table>

Note: ▲ = Theme(s) aligned with the description of thematic component; X = Theme provided an expanded perspective of the thematic component
provided appropriate supports (n = 6) reported positive associations with blindness in childhood. These individuals told stories about how their families fostered their physical and emotional growth, mobility and independence, social inclusion, and access to the blind and/or disability community. On the contrary, participants whose families struggled to understand blindness and/or provide a home environment that was responsive to their disability-related needs (n = 2) reported significant emotional and social struggles. These participants described feelings of shame and fear about being blind, communication difficulties, a sense of isolation (including within the family unit), and a lack of access to mobility training and vision supports. Although all individuals in the sample grew to develop an affirming disability identity, participants who were raised in a family that was accepting and supportive described fewer social-emotional barriers to positive identification with blindness in childhood and adolescence than those who were raised in a family that held negative views of blindness or did not adequately respond to their needs.

Societal Misperceptions of Blindness

*Societal misperceptions of blindness* was found to be a theme of the second thematic component (i.e., social exclusion) and an underlying factor of all other thematic components in this analysis. Societal misperceptions are negative views and false beliefs about the abilities, capabilities, and value of people who are blind. They include stigma, stereotypes, and prejudicial attitudes about blindness. For individuals in this study, societal misperceptions were found to result in experiences of social exclusion, marginalization, oppression, and discrimination.

Participants talked in depth and at length about the detrimental impact of societal misperceptions on their psychosocial well-being and functioning. All eight individuals identified
societal misperceptions as major, aggravating factors to the barriers that they faced in employment, education, social settings, relationships, and the community. Participants expressed feelings of frustration, sadness, despondence, and anger in sharing these stories. Three individuals spoke to internalizing a sense of “wrongness” about themselves in confronting the ways in which blindness set them apart from others. Others talked about the need to psychologically negotiate negative or conflicting messages about blindness in forming a solid sense of self. For these individuals, the development of an affirming disability identity required that they consciously reject dominant societal views that blindness made them incompetent, dependent, or lesser in value. One participant described this as an “exhausting and ongoing process of moving against the grain of society.”

Despite the overtly negative implications of society’s views of blindness, participants talked about feeling motivated to actively work to change them. Six individuals stated that they participate in awareness education activities in which they use a variety of means and tools (e.g., creating digital content, social media, guest speaking) to share information about blindness. Their intention is to present accurate portrayals of what it is like being blind and help remove barriers that keep blind and sighted people apart. Some of these participants spoke to feelings of authenticity, pride, and empowerment in sharing their experiences with sighted people. Others spoke to feeling a sense of personal responsibility toward others who are blind. Their disability identities were found to be deeply rooted in the blind community and connected to its goals of independence, access, and societal inclusion.
Educational Support

*Educational support* was also identified as a factor that influenced the disability identity development of participants. Educational support included classroom accommodations, assistive technology, materials in alternate format, TVIs and vision support services (e.g., orientation and mobility services, Braille training), and classes or activities that addressed the unique needs of blind learners. All eight individuals in this sample shared stories that illustrated challenges to obtaining appropriate educational supports. These difficulties were found across all levels of formal education – from elementary school through college. Among the most frequently reported issues included: the inability to obtain books and materials in alternate format (n = 6); difficulties in obtaining appropriate accommodations (n = 5); inability to participate in sports and school-related activities (n = 5); and, limited or no access to Braille training (n = 3) and orientation and mobility services (n = 2). The implications of these issues were highly negative across the sample. Participants stated that a lack of educational support resulted in learning difficulties (n = 8), poor academic performance (n = 5), an inaccurate understanding of their academic potential (n = 4), the inability to explore and develop their interests (n = 4), and punitive responses from teachers or school professionals (n = 2). These experiences were associated with feelings of frustration, anger, and low self-worth. Several participants shared the ways in which these school experiences had a negative impact on how they perceived blindness and perceived themselves. This impact was found to be especially apparent and detrimental in middle school and high school when individuals were beginning to explore who they are and with which social and cultural groups they belong.
One narrative from this study illustrated the positive impact of access to appropriate educational support. This was found in the story of the only participant who attended a residential state school. This individual shared several stories of how she started to thrive academically, socially, emotionally, and vocationally after transferring to the school at the age of 10. She described herself as having “come to life,” transforming from someone who was quiet, shy, and socially isolated to someone who was “exuberant,” “outgoing,” and full of joy. She also shared the ways in which being surrounded by blind peers and the blind community fostered her independence, inclusion, and positive views of blindness. Through these connections, this participant not only discovered who she was as a blind person but came to develop a sense of pride and empowerment in blindness, which she stated has served to enhance all aspects of her personal and social life.

**Access Barriers**

Participants identified access barriers as a primary factor impacting their integration into society. All eight individual in the sample cited negative attitudes about blindness to be among the most pervasive and preclusive type of barrier. This was followed by inaccessible technology (n = 7), inaccessible written or digital content (n = 7), poor environmental design (e.g., lack of curb cuts, no Braille signage) (n = 6), and a lack of funding to support access to assistive technology and services (n = 3). Nearly the entire sample (n = 7) stated that access barriers are part of their daily lives. One participant said that access barriers “sometimes, but not frequently” were associated with feelings of frustration, annoyance, loneliness, and invisibility. Participants reported feelings of frustration, annoyance, loneliness, and invisibility related to these barriers. Such feelings inhibited positive identification with blindness.
All participants identified self-advocacy as an effective mitigating strategy to reduce or remove access barriers in their environment. Most participants discussed access as an act of social responsibility rather than a legal issue. They used words such as “simple,” “straightforward,” and “easy” to describe the effort that is required to ensure the accessibility of common products and services. Although all eight in the sample self-expressed knowledge of the ADA, only three said that they routinely addressed the ADA in exercising their access rights. Several participants (n = 6) discussed access in terms of society’s regard for people with disabilities. They expressed views that levels of access signify the extent to which disabled people are viewed as equal and valued members of their communities. To them, access was a powerful expression of inclusion – that society desired for them to belong as much as they desired to belong to society.

**Blind Community**

This analysis found that connection with the blind community was central to disability identity development. All eight participants talked about the importance of the blind community to who they are and how they view blindness. They also discussed its role in helping them grow in independence, confidence, and pride. Participants shared that their experiences within the blind community are unique compared to experiences in a sighted society. They talked about feeling visible, understood, and accepted when they are among others who are blind. They also talked about feeling free to simply be without needing to explain themselves or prove their abilities, which is a welcome relief in a sighted world that regularly demands that they satisfy their curiosity and dispel their doubt. One participant shared that when he is with others who are blind, his sense of having an impairment disappears. Several others (n = 4) shared that being part
of the blind community is empowering and what gives them the courage, skills, and motivation to go into a sighted world and achieve their goals.

Individuals in this study were introduced to the blind community in variable ways and times in their lives. One participant had a mother who was disabled and active in the disability community, therefore he had been exposed to the disability community since birth. One was not introduced to the blind community until late adolescence when he received independent living training at a center for the blind. The remaining participants were introduced to the blind community in childhood through school and camp experiences. Their stories highlighted the importance of these connections, especially in childhood and adolescence when they were learning what it means to be blind. Many participants talked feeling “normal” and happy around their blind peers, which was a stark contrast to the cruelty and bullying that they were accustomed to enduring at school. They talked about feeling less lonely and less alone. They also talked about the importance of learning from other blind peers who could understand the world from their shared perspective. One participant said that when they were with their blind friends, they were “finally not teased or embarrassed” to use his white cane. “It was finally okay to be me,” he said.

This experience of acceptance and mutual understanding was critical to their psychosocial wellness across the lifespan. The blind community rooted them in a sense of belonging as they actively worked to achieve that in society. For many in this sample, their connection to the blind community supported an identity that grew to become an outward declaration of pride in blindness. For others, the blind community played a role in their growth to embrace blindness as an integral part of who they are – as an aspect of themselves that makes them whole and an aspect of life that keeps them connected to one another.
Other Blindness-Related Factors

There were two blindness-related factors identified in this analysis that were central to the disability identities of participants and how they expressed themselves in the world. The first of these factors was Braille. Five individuals in the sample were Braille readers. They stated that access to Braille is critical to the integration of blind people in society. It is a means to fulfilling their right to equal access to information and connection to the world. Two participants spoke in detail about the significance of Braille to their identity as a blind person. One of these individuals said that Braille connects her to the roots and experience of blindness. It is a tangible expression of her identity – both physically and culturally. The other spoke about Braille being a source of pride. She said that Braille is a “celebration” of the blindness that is the essence of who she is.

The second factor identified in this analysis was the white cane. Like Braille, some participants (n = 3) shared the importance of their white cane to who they are as a blind person. These individuals considered their white cane to be both a physical extension of their bodies and physical sign of their identification to blindness. Participants expressed feelings of fondness, gratitude, and pride when talking about their white canes. One participant talked about it being her eyes. Another, her “fairy wand.” To them, the white cane is a symbol of their right and freedom to explore the world. This was a stark contrast to the stigmatizing view of the white cane that is commonly adopted by society. Notable, too, was that two participants in this study preferred to use a guide dog for mobility rather than a white cane because of how many people respond to it with fear and avoidance. These individuals stated that their white cane tends to “push” people away, and thus, causes them to feel farther away from others. They expressed that their guide dog allows them to interact in society in a way that was consistent with how they feel.
That is, that they feel part of society, not separate from it. And they desire to invite people into knowing them as much as they want to be known for who they are, blindness and all.
CHAPTER 5

DISCUSSION

The purpose of this study was to conduct initial, exploratory steps to formally test Gill’s (1997) model of disability identity integration and development. As previously mentioned, Gill’s model represents one of the first and most well-developed models of disability identity in the extant body of research. It has been a pillar of theoretical growth in understanding how people come to form identities around disability. This study thoroughly examined the first type of disability integration defined in Gill’s model (i.e., *coming to feel we belong*) in a sample of people with congenital blindness. Using a participatory action framework, this narrative study examined the psychological, social, and cultural factors and experiences that influenced how individuals came to understand blindness and who they are as people with disabilities. The results of the analysis, expressed through voices of blind people themselves, were among the first and only qualitative results on disability identity in blind people to be reported in the literature. Findings from this study are intended to contribute to the growing body of research on disability identity, especially as they relate to the blind population, and help drive theoretical developments that translate disability research into culturally competent rehabilitation practice.

This chapter contains a discussion of this study’s findings and implications for future research. This discussion will illuminate disability identity as a critical component of the psychosocial well-being and functioning of many who live with disability. It will also support Gill’s (1997) model as a useful and applicable model to explain the disability identity
development of people who are blind. This study was unique in that it was among the first to
formally test a model of disability identity development. The Life Story Interview
methodological approach provided for an in-depth exploration of multiple facets of a person’s
life through which to investigate Gill’s model. This allowed the researcher to gain a longitudinal
perspective of an individual’s growth and development across the lifespan. Moreover, the
participatory action framework actively sought to remain informed by people with disabilities in
all aspects of the study. Together, these elements allowed the researcher to thoroughly address
the research question: How do the psychosocial factors and experiences related to the disability
identity of people with congenital blindness align with the thematic components of Gill’s (1997)
first type of disability integration (i.e., coming to feel we belong)?

Interpretation of the Findings

As identity development is understood to be a dynamic, social phenomenon that involves
both individual and group components (Adams & Marshall, 1996), this study was designed to
explore disability identity development within the context of a person’s interactions with their
social environment. This focus provided for a thorough examination of the process by which
blind individuals come to assert their right to inclusion in society according to the theoretical
principles of coming to feel we belong (Gill, 1997). Findings from this study support those from
previous research that suggest that disability identity is largely influenced by a person’s beliefs
about disability and elements of the social environment in which they function (Darling, 2003;
Dorozenko et al., 2015; Kinavey, 2006; Zhang & Haller, 2013). This study identified several
psychosocial factors that impacted how individuals came to identify with blindness and integrate
it into their understanding of themselves. Among the most prominent factors included: (a) family
response to blindness, (b) societal misperceptions of blindness, (c) educational support, (d) access barriers, (e) blind community, and (f) other blindness-related factors. These factors were intertwined and expressed through the themes of disability identity that emerged in the narratives. They draw attention to the significance of the physical environment, attitudinal climate, and social setting in how people who are blind form beliefs about blindness and their right to inclusion in society.

The formal testing of Gill’s (1997) model involved assessing for the “fit” of the themes of disability identity identified in the narratives within the framework of the five thematic components identified by the researcher in her analysis of *coming to feel we belong*: (a) confronting difference, (b) social exclusion, (c) desiring inclusion, (d) asserting rights, and (e) expecting access. There was a total of 12 themes of disability identity identified in the sample consisting of eight narratives. They were defined as: (a) internalizing a sense of separateness, (b) conceptualizing the meaning of blindness, (c) awakening to self-potential, (d) bullying and mistreatment, (e) access barriers, challenges to employment integration, (f) positive peer support, (g) effective self-advocacy, (h) collective empowerment, and (i) access as an expression of unity and belonging. These themes encompassed participants’ beliefs, desires, responses, and experiences as blind people navigating a sighted world.

Results from the analysis indicated that eleven of the twelve themes directly aligned with one of the five thematic components of *coming to feel we belong*. There was one theme (i.e., awakening to self-potential) of *confronting difference* identified in a single narrative that presented as an anomalous finding. *Awakening to self-potential* described an initial, positive response to confronting blindness rather than a negative one. Although this was a stark contrast to the other themes of *confronting difference*, it was not in conflict with Gill’s theory, as it still
exemplified association with one’s minority, disability group in recognizing the disability-related differences that set them apart from most of society. The value of Gill’s model is suggested by the strong thematic congruency between coming to feel we belong and the lived experiences of participants in this study.

Following is a discussion of the major findings of this study organized according to the five thematic components of coming to feel we belong (Gill, 1997). These findings will be presented in the context of this research study and in connection to the body of literature on disability and disability identity development.

Confronting Difference

Confronting difference was the first thematic component identified in the researcher’s analysis of coming to feel we belong (Gill, 1997). Confronting difference involves individuals growing into awareness that having a disability sets them apart from others in society and causes them to be regarded as members of a marginalized social group. There were three themes of Confronting Difference that emerged in the analysis: (a) internalizing a sense of separateness, (b) conceptualizing the meaning of blindness, and (c) awakening to self-potential. Each of these themes highlighted the socially mediated process involved in formulating ideas and views of disability in childhood and adolescence. These ideas and beliefs were found to be formed within the context of a person’s social environment. For participants in this study, this included their family unit, cultural setting, peer groups, and connection to the blind community. The influence of family response to blindness on self-perceptions of blindness was found to be particularly salient to disability identity within the framework of Confronting Difference.
The Influence of Family Response on Perceptions of Blindness

Family response to blindness was found to exert considerable influence over how participants came to an early understanding of blindness and what it meant for them. As all individuals in this study were born blind, their interactions within their family unit represented their first experiences being part of a social world. Family responses to blindness were found to be highly individualized, influenced by innumerable factors, such as a family’s culture, background, access to resources, personal experiences, and perceptions of disability.

Findings from this study indicated that children internalized the views of blindness adopted by their families and mirrored their emotional experiences to blindness. This, in turn, affected the trajectory of their disability identity development. For example, participants who were raised in families that were accepting of blindness and responsive to their disability-related needs stated that they have always viewed blindness as a natural part of who they are. These participants told stories of how their families embraced blindness, advocated for their inclusion, and effectively adapted together to the challenges of blindness. Their families also took an active role in introducing them to the disability community and other blind children. These early life experiences helped to validate their self-worth and fostered positive identification with blindness. Moreover, they created opportunities to establish positive connections with the disability community that seemed to serve as a buffer against adopting negative views of blindness.

In contrast to these participants, those who shared that their families struggled to understand or cope with their blindness experienced significantly more barriers to positive identification with blindness in childhood and adolescence. These participants shared how their family’s struggle had a direct and negative impact on their emotional, behavioral, and social
well-being. They spoke of inadequate access to services and supports for their blindness that led to social isolation at home, at school, and in the community. Most endured access barriers, bullying, and emotional struggles without the psychologically safe “landing space” of a family that could affirm their value and advocate for their needs. This caused them to internalize a sense of separateness from others, even within their family unit, and a sense of “wrongness” about blindness. Although these individuals grew into affirming disability identities by early adulthood, their identity development process was described as psychologically and socially tumultuous, as it required them to confront and internally resolve deeply engrained feelings of shame, self-consciousness, and inadequacy about being blind.

The impact of a family response on a person’s disability identity development has not been empirically examined. Therefore, the findings from this study can only appreciated within the context of the personal life stories shared by participants. Significant to this discussion was that participants underscored the importance of their families’ perceptions of blindness on the development of their own. Participants whose families rejected views of disability as tragic, coped in healthy ways, and provided them with appropriate supports thrived together through blindness. These stories were illustrative of findings from previous research that indicated that disability may have a positive impact on families (Blacher et al., 2013; Kimura & Yamazaki, 2013; Lakhani et al., 2013; Scallan et al., 2011 Vilaseca et al., 2013), highlighting their resilience (Farrell et al., 2014; Smith et al., 2014; Woodman, 2014) and capacity for transformational growth (Scorgie et al., 2001). However, participants who were raised in families that struggled to cope with blindness on psychological and social levels experienced significantly more barriers to positive identification with blindness in childhood and adolescence. Similar struggles of parents who have children with disabilities (Hsiao, 2017), and specifically blindness (Erin et al., 1991;
Hancock et al., 1990; Sakkalou et al., 2017), are documented in the literature. These findings point to the need for further exploration of disability identity development within the context of the family unit, especially with consideration for factors that are germane to specific disability and cultural groups.

**Social Exclusion**

*Societal Misperceptions on Inclusion*

In exploring disability identity within the framework of Gill’s (1997) model, findings show that misperceptions of blindness are barriers to access in society and barriers to positive identification with blindness. Participants unequivocally identified negative views of blindness
as one of the most pervasive and preclusive barriers to their inclusion. They explained the push for inclusion as an uphill battle to assert their value and self-worth against society’s standards of independence, capability, strength, and achievement. Such views are consistent with the voiced perspectives of people with disabilities contained in the contemporary body of disability literature (Wong, 2020). Moreover, findings suggest an interdependent relationship between access and positive identification with blindness. This highlighted a dynamic, reciprocal relationship between a person and their social environment. For those in this study, this was evidenced in how their experiences of access in the community supported positive self-views and self-perceived feelings of acceptance by others. Conversely, encounters with barriers to access—whether physical or attitudinal—were associated with negative emotions about blindness, low levels of expressed self-worth, and feeling invisible or devalued by society.

The impact of societal misperceptions of disability on identity development are documented in the research. Implicit and explicit bias against people with disabilities, whether born of ignorance, fear, misunderstanding, or hate, has been found to impact the self-views and identities of people with disabilities (Darling, 2003; Dorozenko et al., 2015; Kinavey, 2006; Olkin & Pledger, 2003; Onken & Slaten, 2000; Zhang & Haller, 2013). Ostrander (2008), for example, found that men from racial and ethnic minority groups who had sustained violent, acquired spinal cord injuries struggled with integrating the injury into their social roles and sense of self. This was due to negative, societal messages about disability that were in direct conflict with participants’ sociocultural expectations of what it means to be a man. Similarly, Mogensen and Mason (2015), who examined disability identity in adolescents with Autism Spectrum Disorder, found that the self-perceived meaning of an Autism label prevented participants from positively associating with their disability. Their research emphasized the importance of
addressing disability-related stigma and resulting experiences of marginalization in promoting positive identification with disability.

The findings from this study are consistent with those of these previous studies and contribute to the existing body of disability identity research. This study also presents findings that expand the discussion of disability identity in relation to societal misperceptions. Some stories shared by participants, especially those of young adulthood and beyond, were illustrative of resilience and empowerment even in the face of negative views of blindness. Pivotal to their identity development was the ability to negotiate societal misperceptions without internalizing them. Their narratives expressed themes of unity, community, and pride, which moved individuals into active resistance against society’s interpretation of blindness and into a definition of their own. These themes were most frequently formed within the context of relationships within the blind community. These relationships had a direct impact on individuals’ self-views of blindness and their capacity for engagement in the community.

Gill’s (1997) model provides a theoretical framework to explain these findings. Within the context of coming to feel we belong, Gill addressed the role of the disability community in paving the way for people with disabilities to assert their equality and right to belonging. She emphasized the importance of group identity in the development of an affirming sense of self. Gill’s model effectively explains how participants were empowered into inclusion by way of the unity and strength in blindness that they found in the presence of each other. Her model also explains how some of these individuals, in integrating disability into their understanding of themselves, were moved beyond acceptance of their differences into a celebration of them, with and among others.
The Blind Community as a Source and Facilitator of Identity Growth

*Positive peer support* emerged as a theme associated with social inclusion. It described positive interactions with both blind and sighted peers as well as the broader blind community. It was found to harness an exceptional level of social power, supporting a person’s inclusion in groups, roles, and their community. It was also found to have a positive impact on person’s self-development and self-perceived, psychosocial well-being. All eight participants in this sample spoke to feelings of acceptance, pride, joy, and belonging in sharing stories of how these relationships nurtured their growth through every stage along their journey of becoming.

Connection with the disability community has long been regarded as a source of unity and belonging for people with disabilities (Longmore, 2001; Nielson, 2012; Rembis & Kudlick, 2018). In fact, all contemporary models of disability identity presented in this research project incorporated a group component to identity development (Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997; Putnam, 2005). Along with Gill’s model, these models describe the disability community as both a source and a facilitator of positive identity development. Consistent with findings from previous research (Abrams & Salazar, 2005; Bogart, 2014; Bogart, 2015; Bone, 2017; Caldwell, 2011; Evans, 2017; Gilson et al., 1997; Hahn & Belt, 2004; Miller, 2017; Putnam, 2005), this study found that connection with the blind community was central to the formation of a positive disability identity. Participants shared an abundance of stories that illustrated how the blind community nourished the roots of their identity growth. Some described it as a “safe space” where they were free to simply be without the need to minimize, apologize for, or explain their blindness. Within their community, blindness was simply regarded as an integral aspect of who they are. For many individuals, these
interactions were a catalyst in “changing the script” of blindness—in transforming their views, and the views of others, of blindness as unfortunate, pitiful, or wrong to views of blindness as a natural difference, or even a source of strength and pride.

Although this study investigated disability identity within the framework of coming to feel we belong, these findings also exemplified elements of Gill’s second type of disability integration (i.e., coming home). This was not a surprising finding, as all eight individuals in this study’s sample were found to have affirming disability identities. Participants shared stories that expressed endearment for the blind community and gratitude for how it has led them to find their own meaning in blindness. Their feelings and experiences are eloquently captured with Gill’s words of coming home:

While continuing to value their relationships with non-disabled friends and family, they recognized a level of connection unique to their relationships in the disability community. They describe this connection in various ways. Some mention ‘acceptance.’ Others emphasize the ease they feel in talking with others who understand them without the need to stop and explain experiences and terms related to living as a disabled person. Many have ‘started to articulate a sense of disability ‘community,’ ‘culture,’ or even ‘family.’ However, the description of experience that I find most interesting and that I hear often these days – especially from individuals who discover the pleasures of such companionship after years without it – is the simple and poignant phrase, ‘coming home.’ (p. 43)

Desiring Inclusion

Desiring inclusion was the third thematic component identified in the researcher’s analysis of coming to feel we belong (Gill, 1997). Desiring inclusion describes the desire of individuals with disabilities to be included in society. This includes equal access to the same activities, opportunities, and social roles as nondisabled people. Thematic evidence of desiring inclusion was identified across the sample and across all life stages. Participants unambiguously testified to an internal and persistent yearning for inclusion. Individuals told stories of their
tireless push for inclusion on both individual and group levels. They spoke of unrelenting efforts to “prove” their worthiness and capability in the midst of ignorance and indifference. They repeated, again and again, about society’s misunderstanding of blindness, which at times, left them feeling invisible and discardable. Yet, it was precisely these experiences of exclusion, isolation, and disregard that awakened individuals to the social implications of their marginalized group status. For many in this study, this seemed to heighten their desire to be included and, even more so, to be *invited* into community with others. In this way, Desiring Inclusion represented a crossroad between passive awareness of difference and active response to exclusion – a point that served as a vital impetus for movement toward an assertion of belonging.

**Experiences of Invisibility in Society**

The theme of invisibility emerged throughout the analysis of Desiring Inclusion. Invisibility, in the context of this study’s findings, referred to a person feeling overlooked, ignored, and disregarded by society due to blindness. These feelings arose in concert with continuous encounters with access barriers, often despite ambitious advocacy efforts. Invisibility translated into the inability to access the same places, products, activities, services, and job opportunities afforded to their sighted counterparts. Some participants talked about how even with the ADA, blind people seem to be absent from the sight of others. One example provided was how sidewalks are routinely unpassable in the winter months either due to a lack of plowing or by large, piles of snow created from plows that clear the way for motorists. Participants shared that such encounters have not only caused them to question their visibility, but also to question their self-worth and equal membership with the rest of society. Invisibility was found to co-occur with reports of social isolation (e.g., unemployment) and times when individuals had few social
supports (e.g., family, friends, co-workers), both of which are suggested to be factors involved in positive identification with disability (Clarke & Black, 2005; Charmaz, 1995; Cunnah, 2015; Darling & Heckert, 2010; Frank, 1993; Gibson et al., 2005; Raver et al., 2018).

This study found that connection with the blind community had a reversal effect on experiences of invisibility, revitalizing a person’s confidence, self-esteem, and feelings of belonging. Participants shared finding emotional reprieve in community with one another. It was in their togetherness that they felt validated, seen, and valued. Moreover, individuals spoke of acquiring the motivation, resources, and internal strength to be empowered into action to advocate for their needs and establish their rightful place in society. This finding corroborated findings from previous research that has identified that cultural and sociopolitical ties to the disability community to be central to the development of an affirming disability identity (Caldwell, 2011; Dunn & Burcaw, 2013; Gibson et al., 2018; Gill, 1997; Hahn & Belt, 2004; Putnam, 2005).

The theme of invisibility in the context of disability identity development is thought-provoking. Research has explored the identity development of people with “hidden” or “invisible” disabilities (e.g., diabetes, learning disability, depression) (see Charmaz, 1994; Frank, 1993; Gibson et al., 2005; Savaria et al., 2011; Valeras, 2010). These studies have identified factors specific to nonapparent conditions that complicate the development of a disability identity (e.g., fluctuating symptoms, feeling in between the disabled and able-bodied worlds, and not having physical “evidence” of one’s disability status). There were no studies identified in the researcher’s review of the literature that explored the experience of invisibility among people who have visible disabilities. Participants in this study spoke about how the visibility of their disability, along with the associated stigma of blindness, often sparks a fear response in others.
Their efforts to form connections with the sighted world are often stifled by the attitudinal barriers that keep them apart and feeling out of the sight of society. Rather than simply bearing evidence to a life with blindness, they often have to “prove” what blindness does not mean. This appears to be an important area for further investigation, especially for its impact on both inclusion levels and perceptions of the self.

**Asserting Rights**

*Asserting rights* was the fourth thematic component identified in the researcher’s analysis of *coming to feel we belong* (Gill, 1997). This thematic component describes an exercising of one’s rights to access and equality in society. It involves an active response to disability-related barriers, discrimination, and other social disparities that people with disabilities face. Participants stressed the importance of disability rights in their ability to gain access, and successfully navigate, a sighted world. *Effective self-advocacy* and *collective empowerment* were found to be underlying themes of Asserting Rights. Self-advocacy, like the vehicle, and empowerment, its fuel, by which blind people were driven, as individuals and as a community, into society.

**The Role of Self-Advocacy in the Assertion of Rights**

The positive relationship between self-advocacy, the disability community, and disability identity development has been appreciated in the disability identity research (Caldwell, 2011; Hahn & Belt, 2004; Putnam, 2004), but primarily so among activists and leaders in the disability community. This study found a similar, positive association in a sample of blind people who did not self-identify as activists or leaders in disability groups. In exploring the narratives through the lens of Gill’s (1997) model, this study found that connection with blind peers and the blind community fostered positive identification with disability and a sense of personal and group
empowerment. Both are suggested to be factors that drive the assertion of one’s disability-related rights. As achievement of disability integration at the level of *coming to feel we belong* (Gill, 1997) is societal integration, these findings support the significance of group minority identity in integrating disability within oneself and integrating the self into society.

Among the most striking of findings from this study was the naturalness of self-advocacy skills that participants displayed. They told stories that spoke of it as if it had been hard-wired into their DNA. They demonstrated a fluency in the ability to execute self-advocacy that was rooted in self-assuredness and maintained by an almost innate need to protect their rights and dignity. Their effectiveness at advocating was said to have been gained from knowledge of their ADA rights and years of personal experience with access struggles, trial-and-error, modeling disabled peers, and tapping into the acquired wisdom of the blind community. At times, asserting rights took the form of an exhausting fight. Other times, participants described it as a fulfilling and meaningful process, especially when the outcome involved a positive, attitudinal shift or more generalized implications for others with disabilities.

Findings from the analysis indicated a developmental progression to asserting rights. Evidence of self-advocacy was found as early as childhood, although self-advocacy that was demonstrative of a knowing assertion of one’s disability rights (i.e., rights under the ADA) was first identified in the in adolescence. This emergence coincided with Erikson’s (1968) stage of psychosocial development associated with identity development. It also coincided with a life stage of growing independence when many participants confronted, within the context of their peer groups, the psychosocial and functional differences associated with blindness. As they grew into young adulthood and were catapulted more fully into society, their concerns for disability rights increased as they were faced with mounting struggles for access in college, work, and
community life. Individuals shared that being firmly rooted in a blind identity helped them to understand their rights as disabled people and advocate more effectively for their inclusion. They were further strengthened by their relationships within the blind community, which provided emotional momentum to move them from acknowledging their rights to exercising them.

The Collective Empowerment of the Blind Community

As the contents of this chapter discussion argue, the blind community was found to play a vital role in the identity development of participants in this study. The blind community emerged within the context of themes identified in each of the five thematic components of the analysis. Its influence on participants’ understanding of themselves and their place in society was most remarkably noted in asserting rights. It was through these stories that their feelings of empowerment, belonging, unity, and pride were most fervently articulated. And it was here that there was evidence of how feelings were motivated into action. This action expressed their commitment to each other as they worked together, both as a group and side-by-side, to change perceptions of blindness and secure the rights of blind people in society. This finding provides support for a sociopolitical overtone to disability identity development that merges seamlessly into Gill’s (1997) model. It also adds support to the advantageous impact of connection with the disability community on identity development in people who are members, but not activists or leaders, in the disability community.

Collective empowerment was also notable for how it highlighted the resistance and resilience that has played a vital role in securing rights for people with disabilities (Fleischer & Zames, 2011; Goering, 2015). All participants in this study viewed disability rights as human rights. They spoke of inclusion in society as an expectation as much as a right. Although most
discussed their connection to the blind community, all referenced their membership to the
disability community-at-large. Their narratives exposed concern for achieving equality and
inclusion for all disabled people who are disenfranchised in society. Furthermore, they
exemplified the significance of group identity in the development of an affirming sense of self
that integrates, as well as comes to celebrate, disability. Through the process of forming an
identity that included blindness, individuals were drawn into community with one another, and
thus, into an enlivened capacity for integration with the rest of society. This finding encapsulates
the essence of Gill’s (1997) model.

Expecting Access

*Expecting access* was the fifth and final thematic component identified in the researcher’s
analysis of *coming to feel we belong* (Gill, 1997). It states that in understanding equal access as a
societal responsibility, individuals with disabilities not only assert their right to inclusion but
come to expect it. Expecting access represents the apex of integration into society. It underscores
the dynamic interaction of advocacy, empowerment, community, independence, and pride in
developing a sense of belonging that is socially experienced and psycho-emotionally
internalized. *Access as an expression of unity and belonging* was found to be the single theme of
Expecting Access. This theme emphasizes the significance of access on an assertion of
belonging. It expresses a unifying message across the narratives that access is a necessary means
of social inclusion, appreciation for disability diversity, and the collective thriving of
communities. It frames access as a societal, not personal, responsibility – as an expectation as
much as a right. In this way, access as an expression of unity and belonging yields a pull to
belonging rather than merely a push to integrate amidst resisting social forces (i.e., asserting
rights). Thus, it was a thematic illustration of achievement of the first type of disability integration defined in *coming to feel we belong* (Gill, 1997).

**A Vision of Access that is Beyond Accessibility**

The vision of access that participants spoke of contained both environmental and attitudinal elements. They emphatically stressed the latter, however. For those in this study, this vision involved having more than merely *just enough* access via accessibility measures to safely navigate sidewalks, read documents, and enjoy the same features of modern technology available to sighted people. Access required a shift in attitude about blindness. It demands that beliefs about disability, and what it means to be disabled, be informed by the lived experiences and perspectives of people with disabilities themselves. Participants stressed that this understanding of access can only be achieved when blind and disabled people are regarded as equal and valuable members of society. It is through an attitudinal climate of inclusivity and an appreciation for disability diversity that physical access needs are most wholly understood and met. Despite the long-standing, persistent barriers that they and other people with disabilities continue to face, all participants in this study shared feelings of hopefulness in discussing society’s progress in this regard. Their hopefulness was based on having experienced others’ interest and openness to learning more about blindness, increased opportunities to connect with others and share their stories, improved technology, and greater responsiveness from companies and organizations to their access needs.

This description of access emphasizes a reciprocal relationship between a person and their social environment. It draws attention to the influence of the attitudinal structure of systems, groups, and communities on how people with disabilities come to experience a sense of
belonging in society. Participants’ reflections on access revealed themes of equality, advocacy, interconnectedness, community, and justice. They expressed views that resisted mainstream perceptions of disability and called for access to be understood as a societal, not individual, responsibility. These findings evidence Gill’s (1997) last line of text in her description of *coming to feel we belong*, where she stated: “We have dared to expect accommodation for our differentness. We have also dared to place the blame for ‘not fitting in’ more on the creators of restrictive environments, roles, and occupations and less on ourselves” (p. 42). Attainment of such views align with expecting access and, thus, demonstrate achievement of *coming to feel we belong* (Gill, 1997) across the sample of participants in this study.

Limitations of the Study

This study was designed to provide an in-depth exploration of disability identity development while promoting qualitative rigor in the research process. The use of the life story narrative within a participatory action framework is argued to have enhanced the overall quality and rigor of this study. Still, there are several limitations that will be identified and discussed here for their potential impact on the study’s data and the broader implications of its findings.

This study’s small sample size is a clear limitation. Although the sample size was argued to be appropriate given the sample sizes of comparable qualitative studies on disability identity and this study’s purpose, design, and available resources, findings are representative of the sample population and not generalizable to broader disability groups. Additionally, the sample is representative of individuals who met the inclusion criteria of the study and did not face barriers to participate in research. Findings must be appreciated within the context of a small sample of
people with congenital blindness who had access to information about the study and the desire, capacity, and resources to participate.

Social desirability bias is a second limitation. Social desirability bias involves a mismatch between an individual’s genuine reality and the reality that they convey to the researcher (Bergen & Labonte, 2020). It has a negative impact on the data and the interpretation of the findings. The researcher implemented two strategies aimed to minimize the impact of social desirability bias. These included: (a) offering participants remote, screen-free participant options, and (b) applying her professional counseling skills to create an emotionally warm, nonjudgmental research space. Still, as social desirability bias is an intractable factor in essentially all qualitative studies (Bergen & Labonte, 2000), it must be considered as a confounding variable that exerted some influence over the research.

The influence of reflexivity is a third limitation for consideration. Reflexivity refers to the ways that the researcher’s knowledge, perspectives, and experiences shape the research process (Patnaik, 2013). As Malterud (2001) stated, “A researcher’s background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions” (p. 483-484). As previously mentioned, the researcher was the only individual who designed the study and collected and analyzed data. Thus, this research project reflected her own experiential and knowledge-based perspectives. To provide readers a richer understanding of the context in which disability identity development was empirically explored, the researcher acknowledged and articulated her beliefs and position on disability identity that she brought to the study in Chapter 4. Additionally, the researcher used a reflexive journal, which contained her personal reflections about the logistical aspects of the study, her methodological decisions, and
thoughts and feeling about the study as it unfolded. The use of this journal helped to strengthen the integrity of the research process and improved transparency (Lincoln & Guba, 1985).

Another notable limitation of this study is the use of phone interviews to collect the life stories of some participants. Although this may have been advantageous in mitigating social desirability bias by contributing an additional layer of anonymity, a clear disadvantage is that the researcher was unable to access nonverbal cues (e.g., facial expressions, changes in body language) or collect data from secondary sources (e.g., keepsakes, photographs) that supplemented or contextualized verbal data. Additionally, some subliminal elements of interpersonal connection (e.g., physical proximity, touch, and the exchange of emotional energy) were absent. As such, the researcher took extra time with participants before their interview to introduce herself, discuss various aspects of the study, and respond to questions or concerns. Furthermore, the researcher adjusted her speaking pace, tone, and inflection throughout the interview to accommodate the storytelling style of individuals and add a palpable sense of warmth to the interview engagement.

Validity and Reliability

Issues related to validity and reliability are the final points offered for discussion. As previously mentioned, this study was designed to preserve and highlight the voices and lives experiences of people who are blind. A Life Story Interview approach was selected for its methodological value and appropriateness in exploring the research question in a sample of people with disabilities. Atkinson (1998) stated that the analysis of the life story “may have as much to do with the quality and depth of the interpersonal exchange itself as with any theory that
might be applied to the content of the narrative” (p. 59). As such, validity and reliability, as those terms are understood and applied in traditional research methods, must be re-framed and applied to align with the valuative standards of Life Story Interview (Atkinson, 1998). Thus, in assessing the validity and reliability of the life story, the researcher is assessing the extent to which the life story is the full and authentic story of the person telling it (Riessman, 1993).

**Validity**

The validity of a study generally refers to the extent to which a method measures what it claims to measure (Holstein & Gubrium, 1995; Kirk & Miller, 1986). In qualitative research, validity is best applied in terms of the “appropriateness” of the selected methodology (Leung, 2015). There are no formal procedures to determine validity in narrative research, as the main objective of Life Story Interview is to understand a person’s subjective reality rather than establish its historical truth (Atkinson, 1998). However, the researcher applied two control measures that were identified by Atkinson (1998) to help establish and assess for validity. These control measures are known as corroboration and persuasion.

Corroboration for this study involved a two-step process. First, prior to data analysis, participants were required to review a transcription of their interview to validate its content. Participants were able to make changes or corrections to the transcription, if needed, to ensure that it accurately captured the expressed truth of their life story. Second, the researcher consulted with participants about the direct quotes that were selected for inclusion in the final report. This helped to ensure an accurate interpretation of the intended meaning of the data. The second control measure was persuasion, which Atkinson (1998) defined as “an objective measure in which the life story seems reasonable and convincing to others” (p. 61). This standard refers to
the plausibility of the life story (Riessman, 1993). The researcher applied persuasion by carefully reviewing the narratives for inconsistencies within the data or evidence or fanciful storytelling. An example of a potential inconsistency in the data would be a person stating, “Blindness doesn’t impact my life at all,” yet discussing access barriers that impact various aspects of their life. The researcher was mindful to consider differences in storytelling style and abilities that may have arose due to factors specific to blindness (e.g., highly detailed accounts that aid in visualization) when assessing for persuasion.

**Reliability**

Reliability is a measure of the replicability of the study and its findings (Leung, 2015). It is best understood in qualitative research in terms of the consistency of the yielded results. The issue of reliability is more obscure in Life Story Interview as no two researchers will carry out the interview or analyze data in the same or replicable way (Jackson, 1987). Atkinson (1998) argued that a reliable life story is one that renders meaning for the teller and makes sense to its receiver. He stated that a study’s design has much to do with achieving this product. This study used methods and data analysis procedures that have been prescribed for use with Life Story Interview. Additionally, it was designed within a participatory action framework to ensure that it remained informed and guided by people with disabilities. These aspects of this study’s design were intended to promote both its reliability and ethical integrity. However, a clear limitation was the availability of a single researcher to collect and analyze data. The researcher used a multi-level, cross-check process for coding and identifying themes to aid in combatting the impact of this limitation. Still, findings are reflective of solely her analysis and there was no
opportunity during the coding process to strengthen the study’s reliability through establishment of an interrater reliability rating (Belotto, 2018).

Considerations for Future Research

This study contributed important findings to the body of disability identity research. Of significant importance were findings that support the value of Gill’s (1997) model in exploring factors of disability identity development in people with congenital blindness. To date, none of the models of disability identity have been rigorously tested. Moreover, few studies have explored disability identity specifically in blind populations. As such, these findings expand the empirical discussion of disability identity development and offer several considerations to guide future research.

To begin, the researcher urges further investigation of Gill’s model (1997). Although this study found Gill’s (1997) model to be a useful framework to examine the disability identity with reference to the first disability integration type (i.e., *coming to feel we belong*), the remaining four disability integration types have been left unexamined. Research is needed to thoroughly test these remaining components and the model in its entirety, especially in specific disability groups. A complete and holistic perspective of Gill’s framework is needed to fully evaluate its empirical value across diverse disability types and experiences. Validating Gill’s model, and others, will help to advance the theoretical foundation of disability identity research.

Further studies to test Gill’s (1997) model, and others, is also a critical step toward the development of measurement instruments of disability identity. The lack of well-validated measures is a current limitation of disability identity research (Forber-Pratt et al., 2017). Validating existing models may lead to the development of measures specific to the models or
their related constructs. The availability of these instruments would allow for larger-scale studies that would add considerable empirical girth to the body of disability identity research.

Additionally, findings from this study suggest the need to explore disability identity development in highly controlled samples. This study, for example, identified several disability-related variables of identity development that pertained exclusively to people who were born blind (e.g., the blind community, early access to Braille). It is important to delineate disability characteristics, especially when devising inclusion criteria, to identify disability-specific factors that lead themselves to significant patterns and trends in identity development. Consideration for cultural differences is also crucial. This study sought to explore disability identity in people of various ages, ethnic, cultural, and socioeconomic backgrounds. While this diversity was a strength in this study for how it allowed the researcher to test Gill’s (1997) model across a variety of belief systems and life experiences, it is imperative that future research more closely examines the disability identity development of people of specific backgrounds. The intersectionality of disability identity with other identities (e.g., racial, LGBTQI+) was left unexplored in this study. Future research is needed to contribute the voices and lived experiences of individuals with disabilities who identify with multiple, minority groups.

It is also hoped that this study prompts more exploration into the disability identity of people who are blind. This study was among the first studies to provide a rich source of qualitative data about how individuals with congenital blindness come to integrate blindness into their sense of self. Further research, especially using qualitative methods, is needed to add to the existing literature. Studies that examine the disability identities of people with acquired blindness or later onset blindness are also needed, as these types of blindness are most common (Brault, 2012) and present unique psychosocial factors (e.g., adaptation to vision loss) (Falchetti et al.,
2015; Tabrett & Latham, 2012) not relevant to congenital blindness. Such studies will allow researchers to better understand identity development, and its related factors, specific to blindness and various forms of blindness.

This study identified several factors that were found to influence disability identity development (i.e., family response to disability, societal misperceptions, access barriers, blindness-specific factors, and the blind community). Each of these factors warrants further investigation to explore their empirical significance in affecting how disabled people come to perceive disability and themselves. Such data are needed to develop a firmer understanding of the psychosocial variables that underly or predict disability identity formation. They are also vital to developing and testing interventions that impact inclusion levels and perceptions of disability, both of which this study found to be critical components of disability identity development.

Furthermore, findings from this study underscore the importance of future studies exploring disability identity through the lens of the social model of disability (Goering, 2015; Olkin & Pledger, 2003). As people with disabilities are a marginalized minority group, this framework is best aligned to examine the influence of stigma and oppression in how they come to see themselves and their place in society (Crow, 2001; Malhotra & Rowe, 2014; Martin, 2012; Shakespeare and Watson, 2001). Also vital to future studies is the use of a participatory action research design. Participatory action research keeps the voices of individuals with disabilities at the center of research (Balcazar et al., 2006; Baum et al., 2006; Selener, 1997; Whyte, 1991). This is critical to empowering people with disabilities and advancing their status in society.
Conclusion

Disability identity development has been identified as an important part of the psychosocial well-being of many who live with disability (Bogart, 2014, 2015; Cunnah, 2015; Darling, 2013, 2019; Dunn & Burcaw, 2013; Gill, 1997; Nario-Redmond et al., 2013; Raver et al., 2019; Siebers, 2017). Despite its significance, there remains a paucity of research on the topic. Additionally, few theoretical models of disability identity development exist, and of these, none have been rigorously tested. This has presented challenges to advancing the body of research and translating findings into culturally competent rehabilitation practice. This study sought to address these limitations and to do so using a participatory action framework that maintained an emphasis on the voices and lived experiences of people who are blind.

This study aimed to investigate Gill’s (1997) model of disability identity integration and development, which represents one of the first and the most well-developed models in the extant body of research. As no former studies have empirically tested Gill’s model, the researcher limited her investigation to the first type of disability integration (i.e., coming to feel we belong) defined in the model. A thorough analysis of coming to feel we belong performed by the researcher resulted in the identification of five thematic components that encompassed its theoretical tenets. Using a small sample of people with congenital blindness and a Life Story Interview methodological approach, the researcher explored the psychosocial factors and experiences that influenced how individuals came to perceive blindness and integrate it into their sense of self. Concerted efforts were taken to examine identity development within the context of interactions with society and in connection with the disability community. This helped to
illuminate variables pertinent to each thematic component and assess for their theoretical fit within *coming to feel we belong*.

Findings from this study indicated that all participants developed affirming disability identities, yet not without substantial barriers to positive identification with blindness. The most prominent barriers suggested by the results of this study were attitudinal in nature. Stigma, stereotypes, and prejudicial attitudes were found to have a substantial, negative impact on self-views of blindness, inclusion levels, and a person’s sense of belonging. Misperceptions of blindness were described by participants as particularly harmful to their psychosocial well-being and, also, particularly resistant to change. This is juxtaposed with the highly advantageous impact of connection with the blind community and other supportive peers, both blind and sighted. Participants emphatically expressed the positive and lasting impact that these relationships had on how they came to see blindness and see themselves. Moreover, these relationships, especially within the blind community, were found to foster joy, interconnectedness, empowerment, and pride in blindness. These experiences supported intrapersonal and interpersonal growth, which in turn, supported the development of an affirming disability identity that asserted one’s right to inclusion in society.

The researcher argues that the findings of this study aligned within *coming to feel we belong* (Gill, 1997) and lend support to the validity and usefulness of Gill’s model. The researcher also wishes to highlight the immense value of the model for how it echoed participants’ concerns for disability equality and justice. Although this study focused on exploring the disability identity development of a small group of people with congenital blindness, the potential applicability of the model to broader blind populations is suggested by the consistency of the thematic results rendered by the analysis. Further studies and testing of
Gill’s model will enable researchers to establish, with greater confidence, its generalizability across diverse disability types and populations.
REFERENCES


Harniss, M., Amtmann, D., Cook, D., & Johnson, K. (2007). Considerations for developing interfaces for collecting patient-reported outcomes that allow the inclusion of individuals with disabilities. Medical Care, 45(5 suppl 1), S48–S54. doi: 10.1097/01.mlr.0000250822.41093.ca


APPENDIX A

DATA COLLECTION PROCEDURE CHART
Researcher obtains IRB approval for the study

Initiate recruitment activities
Email and telephone outreach to social and professional disability networks to share study-related information and materials

Contact individuals who express an interest in participating in the study
Obtain a brief overview of individual’s demographic and social status (e.g., age, gender, employment, group affiliations)
Keep record of potential participant information and note their schedule availability

Selection of eligible participants

Contact selected individuals to inform them of their eligibility to participate and confirm their continued interest to participate
Assess for accessibility needs and preferences (e.g., preferred format of printed materials)

Final selection of study sample
Minimum: n = 5

Complete and obtain all signed consent forms
Schedule interviews
2 weeks before the scheduled interview:
Contact participants to provide detailed information about the Life Story Interview and guidance on how to best prepare their life story
Answer participants’ questions
Confirm that all accessibility needs have been fully addressed and appropriate accommodations, as needed, are in place

3 days before the scheduled interview:
Send reminder to participants in their preferred format (e.g., text, phone call, email)
Verify telephone number for the day of the interview

1 day before the scheduled interview:
Send reminder to participants in their preferred format (e.g., text, phone call, email)

Conduct scheduled interview

Send transcript of interview to participant for content verification
Revise transcript, per participant request, as needed
If edited, send revised transcript to participants for content verification

Data coding and analysis

Report Findings
Interview Guide

Note: This Interview Guide does not contain an exclusive or exhaustive list of items. Items are intended to guide participants who require assistance in sharing or expanding their life story.

Family of Origin

Anticipated time allotted: 15-20 minutes

- What was happening in your family, your community, and the world at the time of your birth?
- What have you been told about your birth? Are there any family stories told about you as a baby?
- How did your parent/s learn that you were blind? Have they shared anything about how they or other family members/friends reacted to learning that you were blind?
- How would you describe your parent/s? How would you describe your mother’s personality and emotional qualities? How would you describe your father’s? How did your mother’s personality and emotional qualities impact you as a child who was blind? How did your father’s?
- Can you tell me about one of the first times that you remember realizing that you were blind and most others were sighted?
- What did the word blindness mean to you as a young child?
- What were some of the most difficult aspects of being blind in your family?
- What were some of the best aspects of being blind in your family?

Early Life Experiences

Anticipated time allotted: 25-35 minutes

- Tell me more about who [participant’s name] was at age 5.
- Let’s talk about when you first started school. How old were you? What do you remember about your school? How do you recall feeling? Is there anything that stands out to you about this first school experience?
- Tell me more about elementary school? What was school like for you? What was most helpful for you as a student? What were some challenges that you faced? Tell me more about your experiences with peers and friends during this time?
- If you could go back in time and share wisdom with the younger version of you (age 8, 9, 10), what would you say?
- What aspects of your childhood most influenced who you are today?
- Who from your childhood most influenced who you are today?
- Tell me more about who [participant’s name] was at age 12.
- Tell me more about high school? What was high school like for you? What was most helpful for you as a student? What were some challenges that you faced? Tell me more about your experiences with peers and friends during this time?
• If you could go back in time and share wisdom with the teenage version of you, what would you say?
• What did blindness mean to you as a teenager?
• Tell me about a time growing up when you felt excluded because of your disability.
• Tell me about a time growing up when you felt accepted and included even though your blindness may have made you different.
• What did you wish you knew about blindness as a teenager that you now know as an adult?

Cultural Settings

Anticipated time allotted: 15-25 minutes

• What is the ethnic or cultural background of your parent/s?
• Was there a noticeable cultural flavor to your home? Tell me more about it.
• What was it like being someone with a disability who grew up in your culture?
• What did disability (or blindness) mean for someone from the standpoint of your culture?
• What cultural influences are still important to you today?
• Was religion important in your family? How would you describe the religious atmosphere in your home? What was it like for you to attend religious services as a young person?
• What do you remember your religion teaching you about disability (or blindness) as a young person? Was this different from how you saw blindness? How did this make you? Influence how you saw yourself?
• What influence do you see religion having on your life today? How you see yourself? Understand disability?

Education and Work

Anticipated time allotted: 25-35 minutes

• Did you have any dreams or ambitions as a child or teenager about what you wanted to be when you grew up? How did you see your blindness as fitting into that dream?
• What was college (or vocational training) like for you? What were some of the most important things that you learned during this period? Who or what influenced your career choice?
• What were some of the most important things that you learned about yourself during your college years?
• Tell me more about your work history. What types of jobs have you had? What were some of the high points of your working career? Low points? What have you enjoyed most about your work? Least?
• Tell me more about the relationships that you have had with co-workers and supervisors? How has your blindness impacted those relationships? How you see yourself? Your strengths and limitations in the workplace?
• What have your experiences been with advocating for yourself in the workplace? What types of challenges or adversity have you faced in the workplace? How did you respond?
• What are your personal beliefs about the rights of people with disabilities to participate in the workforce?
• How confident are you that you know your rights as a person with a disability in the workforce? What types of supports or resources have helped you develop this knowledge?
• What advice would you give to a teenager who is blind who is starting to explore their career interests?

Relationships and Social Factors

Anticipated time allotted: 25-35 minutes

• Tell me more about the most important relationships in your life right now.
• Share with me more about [person’s partner].
• In what ways does [person’s partner] bring out your strengths? Complement you? Challenge you?
• How has blindness impacted who you are as a partner/parent/friend.
• How have the challenges that you have faced as a [partner/parent/friend] been unique or different because of blindness? In what ways are they the same as they would be for a sighted person?
• What have your experiences been with building friendships? Dating?
• How has blindness influenced how you approach building friendships or meeting new people?
• Tell me more about any access issues or barriers that you regularly encounter. How do you typically respond? How do these encounters make you feel?
• If you could dream of new technology to aid you in performing any task, what would that technology be capable of doing? How might this type of technology change your social interactions?
• What are some of the most challenging attitudes about disability/blindness for you? What makes these attitudes especially challenging?
• Share with me any aspects of society – such as how people think and behave – that prevent you from fully becoming and expressing who you truly are? What do you wish society knew about you?
• What are some of your hobbies or things that you do for fun? What do you enjoy most about these activities?
Beliefs About Disability

Anticipated time allotted: 25-35 minutes

- What does the word disability mean to you now? Has this meaning for you over the course of your life? In what ways?
- What do you see society’s view of disability being? Can you give me some examples of times in your life when you have encountered these views?
- How has society’s response to your disability influenced your beliefs about your disability/blindness?
- What changes are needed for society to have an accurate understanding of what it means to have a disability? What impact would they changes have on your personal life?
- What feelings does blindness/disability bring up for you?
- How important is your blindness to who you are?
- If you were asked to provide five words or short phrases to answer the question, “Who am I?” what would those five words or short phrases be?
- How do you think who you are would change or not change if you were not blind? What types of feelings does thinking about this question bring up for you?

Disability Community

Anticipated time allotted: 15-25 minutes

- Who do you see as belonging to the disability community? Do you see yourself as belonging to this larger community?
- What is it like for you to meet other people who have disabilities or are blind?
- Tell me about any connections that you have with the blind community or disability community. What feelings do you associate with having this connection to a larger community of people with disabilities?
- How important is it for you to associate with other people who are blind/have disabilities? What is it about these interactions do you value most?
- Were there times (or are there times) in your life that you have preferred to stay away from disability-related groups? What were the feelings and/or experiences that were related to this preference?
- What are some of the shared goals of the disability community to which you belong?
- How does belonging to the disability community influence how you see yourself?
APPENDIX C

THEMATIC ANALYSIS OF NARRATIVES
**Phase Two: Thematic Analysis of Narratives**

**Participant:**

<table>
<thead>
<tr>
<th>Theme from Gill (1997)</th>
<th>Themes that supports alignment</th>
<th>Illustrative excerpts</th>
<th>Discussion of common thematic features</th>
<th>Notable patterns or data points of interest</th>
<th>Themes/excerpts that conflicts with Gill</th>
<th>Discussion of conflicting thematic features</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confronting Difference</td>
<td>Individuals with disabilities recognize and confront the psychosocial implications of having a disability and belonging to a socially marginalized group.</td>
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<tr>
<td>Social Exclusion</td>
<td>Individuals with disabilities experience exclusion from society and have been socially conditioned to accept this exclusion.</td>
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<tr>
<td>Desiring Inclusion</td>
<td>Individuals with disabilities express the desire to be included and have equal opportunities in their communities and society.</td>
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<tr>
<td>Asserting Rights</td>
<td>Individuals with disabilities believe that they have the right and capacity to assert their rights to be regarded as equal members of society.</td>
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<tr>
<td>Expecting Access</td>
<td>In understanding equal access as a societal responsibility, individuals with disabilities not only assert their rights to equal access but come to expect it.</td>
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</tbody>
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APPENDIX D

DISABILITY IDENTITY THEMES
### Alignment of Themes Contained in Life Story Narratives with Thematic Components

<table>
<thead>
<tr>
<th>Narrative Source</th>
<th>Confronting Difference</th>
<th>Social Exclusion</th>
<th>Desiring Inclusion</th>
<th>Asserting Rights</th>
<th>Expecting Access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
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<tr>
<td>Theme:</td>
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<td>Participant 3</td>
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<td>Theme:</td>
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<td>Participant 4</td>
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<td>Participant 5</td>
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<tr>
<td>Theme:</td>
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*Note: ▲ = Theme(s) aligned with the description of thematic component; X = Theme provided an expanded perspective of the thematic component*
APPENDIX E

WRITTEN ADVERTISEMENT ABOUT THE STUDY
Are you an individual between 21 and 64 years old who was born blind? Are you interested in sharing your life story as part of a research study on disability identity? Please consider this unique opportunity to let your voice be heard!

As part of this study, you will be invited to share your life story during an in-depth interview with the researcher. The researcher is also someone with a disability and has designed the interview to be accessible, flexible, relaxed, and enjoyable! Your insights and perspectives are needed to help researchers better understand how people with disabilities experience disability and come to integrate disability into their understanding of who they are.

Please contact Lisa Gagliano at 847-221-8611 or lgagliano1@niu.edu if you are interested in learning more.

This study is a dissertation research project that is being conducted and completed by Lisa Gagliano who is a doctoral candidate at Northern Illinois University in the Health Sciences program.

This project has been reviewed and approved by the NIU Human Subjects Committee; Protocol # HS21-0229. Questions concerning your rights as a participant in this research may be addressed to the Division of Research and Innovation Partnerships, Lowden Hall 301, NIU, DeKalb, IL 60115.
APPENDIX F

INFORMED CONSENT FORM
Study Title: Disability Identity Integration and Development in People with Congenital Blindness: An Evaluative Analysis of Gill’s Model

Investigator

Name: Lisa Gagliano  Dept: School of Interdisciplinary Health Professions

Phone: (847) 221-8611

Key Information

- This is a voluntary research study on disability identity development in people who are blind.
- This 2-3 hour study involves individuals participating in a telephone or video interview with the researcher in which they will share their life story.
- The benefits include the opportunity to share insights, perspectives, and experiences on living with a disability to help researchers better understand the process by which people integrate disability into their understanding of who they are. There are no foreseeable risks to participation in this study.

Description of the Study

The purpose of the study is to explore the disability identity development of people with disabilities. This study is interested in examining the psychological, social, and cultural, and disability-related factors that influence individuals’ experiences with disability and who they are as people with disabilities. Additionally, this study will investigate how themes related to individuals’ experiences around disability identity align with theoretical principles of one type of disability integration described by Gill (1997) in her theory of disability identity integration and development.

If you agree to be in this study, you will be asked to do the following things: (1) **Schedule a telephone or video interview with the researcher.** The interview process in its entirety is expected to be approximately 2-3 hours long. However, participants are asked to block out at least three and half hours on the day of the scheduled interview to ensure adequate time for reflection and rest breaks, as needed. (2) **Prepare for the Life Story Interview.** Two weeks prior to the scheduled interview, the researcher will contact participants to share information about the interview, provide helpful tips on how to best prepare their life story, and answer any questions that participants have. (3) **Participate in the Life Story Interview.** Participants will meet with the researcher over the telephone or video to tell their life story. Interviews are expected to take 2-3
Northern Illinois University
Consent to Participate in a Research Study

hours but may be longer or shorter depending on the individual’s needs and storytelling style. (4) **Review the transcript.** One to two weeks after the interview, participants will be asked to review the transcript of the interview. This will provide participants an opportunity to revise or add to their life story if any changes are needed. Also, the participant will be given the option to change names and other identifying information used during the interview to pseudonyms and other code words to protect their anonymity. Furthermore, participants will be given the option to select text from the transcript that they give permission for the researcher to use during the formal report of the research study. (5) **Inform the researcher about your accessibility needs.** You have the right to access all study-related materials, such as this consent form and the interview transcript, in your preferred, accessible format. Please make the researcher aware of your format preferences (for example, documents in large print, audio, or Braille) and accessibility needs throughout the course of the study. The researcher will gladly honor your accommodation requests.

**Risks and Benefits**

There are no expected risks to participation in this study. The benefit of your participation may include the opportunity to share insights and perspectives on living with a disability that will help researchers better understand how people with disabilities experience disability and come to integrate disability into their understanding of who they are.

**Confidentiality**

The records of this study will be kept strictly confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password protected file. Any audio recordings that are made will be saved as password protected electronic files on external USB drives that will be kept in a locked file cabinet. Only the researcher will have access to these audio recordings. The audio files will be erased and the USB drives will be physically destroyed by third party document destruction services at the completion of the research project or within twelve (12) months, whichever is first.

**Compensation**

You will not receive any compensation for your participation in this study.

**Your Rights**

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time. Your decision will not result in any loss of benefits to which you are otherwise entitled. You have the right to skip any question or research activity, as well as to withdraw completely from participation at any point during the process.
Northern Illinois University
Consent to Participate in a Research Study

You have the right to ask questions about this research study and to have those questions answered before, during, or after the research. If you have any further questions about the study, at any time, feel free to contact the researcher, Lisa Gagliano at lgagliano1@niu.edu or by telephone at 847-221-8611 or her Dissertation Committee Co-Chair, Dr. Bryan Dallas at bdallas@niu.edu or by telephone at 815-752-8389. If you have any questions about your rights as a research participant that have not been answered by the investigator or the investigator’s Dissertation Committee Co-Chair, you may contact the Office of Research Compliance, Integrity, and Safety at (815) 753-8588.

Future Use of the Research Data

Your information collected as part of this research will not be used or distributed for future research, even if all identifiers are removed.

Your signature below indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep, along with any other printed materials deemed necessary by the study investigators.

________________________
Participant’s Signature     Date

I give my consent to be audio recorded during the interview with the researcher.

________________________
Participant’s Signature     Date