

*Routledge Approaches to History*

# **DISABILITY STUDIES MEETS MICROHISTORY**

**THE SECRET LIFE OF BÍBÍ IN BERLÍN**

*Guðrún Valgerður Stefánsdóttir,  
Sólveig Ólafsdóttir, and Sigurður Gylfi Magnússon*



# Disability Studies Meets Microhistory

This volume explores the life of Bjargey “Bíbí” Kristjánsdóttir (1927–1999), an Icelandic woman with intellectual disabilities, through analysis of her autobiography and personal archive on the basis of the research disciplines of critical disability studies and microhistory.

Bíbí, who grew up in northern Iceland on a small farm called Berlin, fell ill when she was in her first year and was afterward labeled “feeble-minded” by her family and the local community. When Bíbí died, she had finished a 145,000-word autobiography which she had written alone and kept secret from her family and neighbors, very few of whom even knew that she could read and write. This book aims to consider Bíbí’s life through her autobiography and other historical sources she created, to identify how various historical, social, and cultural factors interacted and influenced her circumstances. It explores Bíbí’s agency, and how she managed to play her cards within the narrow scope given to her by society. What makes Bíbí’s history extraordinary is precisely the direct connection to her world through her counter-archive.

This book provides students and scholars of the humanities and the social sciences with a new way of critical thinking about both disciplines.

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Guðrún Valgerður is a professor in disability studies and Sigurður Gylfi is a professor in cultural history with a special focus on the methods of microhistory, both at the University of Iceland. Their challenge was to intertwine these two disciplines in dealing with this complicated material which the life of Bíbí in Berlín was. We believe that one of the most important contributions of this book is this attempt to work out a methodology that draws from both approaches.

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# 1 Introduction

## How to Combine Critical Disability Studies and Microhistory

The introduction provides an exposition of Bíbí's unusual story and discusses the state of the art in such research. It goes on to discuss the scholarly disciplines to be applied in the study, i.e., critical disability studies and the methods of microhistory. Through these approaches, the opportunity arises to address the highly unusual life course experienced by Bíbí in a new and interesting way. Bíbí's story has few parallels, from whatever angle it is considered. Much has been said and written on the subject of people who found themselves in institutions, but far less about those who remained in their own communities, mostly among "normal" people, becoming a part of the everyday social environment. The introduction explores the meaning of her life in a very hostile environment.

### The Story in Brief – Bíbí in Berlín

Bíbí, whose full name was Bjargey Kristjánsdóttir (1927–1999), was known by the name of her parents' farm, Berlín, which was located just outside a small village called Hofsós in north Iceland. Bíbí was considered a promising child, but she fell ill in her first year and was later labeled "feeble-minded" by the medical profession, her family, and the community at large. Bíbí was long hidden at home and kept away from guests and visitors. She did not attend school but was educated at home, learning to read and write. She lived on the farm in Berlín with her parents and brother until 1958, when her mother suddenly died. Bíbí was then 30 years old. After that, attempts were made to have her admitted to *Kópavogshælið* (the Kópavogur Institution) for people with intellectual disabilities near Reykjavík, which had opened some years earlier, in 1952. Bíbí refused to go, and she got herself way. Instead, she was found a home in a neighboring town where she did not know anyone, in *Héraðshælið* (*Hælið*), a residential home for the elderly in Blönduós, north Iceland. There, as a young person, she lived among elderly people for 17 years, until 1974.

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## 2 Introduction



*Figure 1.1* Bibí in Berlín – Bjargey Kristjánsdóttir

*Source:* Regional Archives, East Húnavatnssýsla: from the archive of Sigursteinn Guðmundsson.

*Notes:* This photo was probably taken around 1974, when Bibí moved out of *Hælið* to live independently in Blönduós. She had moved into the institution at the age of 30 after the death of her mother. She lived there for nearly 17 years until she moved out to make her home in the village.

Bíbí was thus 47 years old when, according to her own account, she achieved “independence” in Blönduós when she moved out of the institution and into the small town. For the first few years, she lived alone in a room rented for her by her friend Ingibjörg Sigurðardóttir, or *Dear Imba*, as she called her, who worked at *Hælið*. She later moved into a small, detached house, which was bought with the help of *Dear Imba*; the house is known today as Bibí’s House. She lived there until 1992, but by then, her health had deteriorated, and she moved back into *Hælið*, where she died in 1999 at the age of 72.

After Bibí’s death, it transpired that she had written an autobiography, a book that was 145,000 words (the average monograph is around 90,000 words).<sup>1</sup> Bibí’s autobiography and other source material that she created attest to her intelligence, rich imagination, and insight into her own circumstances and those of her peers. Her writing is at times magnificent, and her imagery is ornate and often poignant. It is safe to say that she did

not spare her contemporaries in her judgments. It is clear that Bíbí wanted her manuscript to be published, even though she kept her writings hidden from most of her contemporaries, and in fact, few people were even aware that she could read and write.

Bíbí's autobiography is a unique source, as well as other source material she created, that has given us an opportunity to understand much better the status of those who were on the margins of society, not least disabled girls and women. In addition, her story provides a unique insight into the life and experience of a woman who was ostracized from human society, sidelined, and denied access to traditional institutions of society such as the education system and, indeed, even the healthcare system. She was alone in her own way in the world, especially after her mother died, but she still managed to deal with her situation in an admirable way. Her gardening, a sizeable library, and her doll collection are chapters in Bíbí's story; all this, along with the manuscript of her autobiography, poetry she composed, and a diary she kept for years, provide an opportunity to analyze her personality and the society that she was, after all, part of.

### **The 20th Century in Iceland**

Iceland is an island of about 103,000 square kilometers located in the North Atlantic Ocean. Previously uninhabited, it was settled in the 9th century, mostly by farmers of Norwegian extraction, as part of the Viking migrations. By the 11th century the population had reached 70,000, around a third of that of Norway at the time.<sup>2</sup>

Iceland was incorporated into the Kingdom of Norway in the latter half of the 13th century, and subsequently, in 1383, it followed Norway when the Norwegian and Danish kingdoms merged. From then, up until the 20th century, the Icelanders were subjects of the Danish crown. Despite this, the people retained a distinct culture shaped by their harsh and isolated island environment. Notably, the Icelanders spoke their own language, which by the later Middle Ages was incomprehensible to speakers of the mainland Scandinavian languages. Icelandic remained close to the Old Norse brought by the original settlers, while Norwegian, Danish, and Swedish diverged considerably under the influence of other European tongues.<sup>3</sup>

The history of Iceland in the 20th century can be divided, without serious oversimplification, into two periods before and after 1940. Up until 1940, Iceland was best viewed as an essentially agrarian and, to some extent, insular society. The country underwent a number of significant changes in the latter part of the 19th century and the early 20th century, but these had caused little fundamental disruption to people's existing cultural outlook and ways of thinking. Society was grounded in the

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traditional peasant values of thrift and financial restraint, combined with conservative attitudes in matters such as culture, class structure, human relations, and living standards. The great change came with Iceland's enforced emergence on the international scene when the country was occupied by British forces in 1940 to secure Allied control of the North Atlantic in World War II. US troops took over from the British in 1941. In 1944 the modern Republic of Iceland was founded, ending the historic relationship with Denmark. In 1946 a defense agreement was concluded with the United States, permitting continued American military presence on Icelandic soil. This agreement proved highly controversial and split the nation into bitterly opposing political camps.

The latter part of the century was a time of rapid change in all areas of society. In the years after the war, commerce and growing contact with the outside world had an ever-increasing impact on material and economic conditions in Iceland. These developments were accompanied by profound changes in the cultural outlook. Once again, however, this did not involve a complete and unconditional rejection of the traditional values of agricultural society, which continued to play an important part in people's lives and perceptions until well into the second half of the century. Despite the rudimentary infrastructure and the fragility of the formal institutions of state, Iceland's cultural heritage remained strong, unified, and largely intact.

Most Icelanders seem to have derived enormous strength from their shared cultural background, centered on their common language, eleven hundred years of recorded history, and a strong tradition of literature and literacy. The cultivation of literature and poetry, which often demanded the systematic application of abstract concepts, proved exceptionally useful to many people when faced with the new, industrialized world of the 20th century. Icelanders appear to have found the leap from the turf cottages of the 19th century to the steam trawlers and mechanized technology of the modern age comparatively easy and accomplished the adjustments needed without losing their links to the past. This attribute – the readiness to embrace the new while holding on to customs and attitudes developed over the centuries – has left its mark on the country's culture and economy and undoubtedly helped it to establish its position among the community of nations during the course of the 20th century.

The life and story of Bibí spans a large part of the 20th century; during her lifetime, prevailing trends and currents ranged from eugenics, genetics, and a complete isolationist policy concerning disabled people to demands for human rights and full social participation. During this period, significant societal changes took place regarding the affairs of disabled individuals and the campaign for equality in general. Bibí's life span has given us

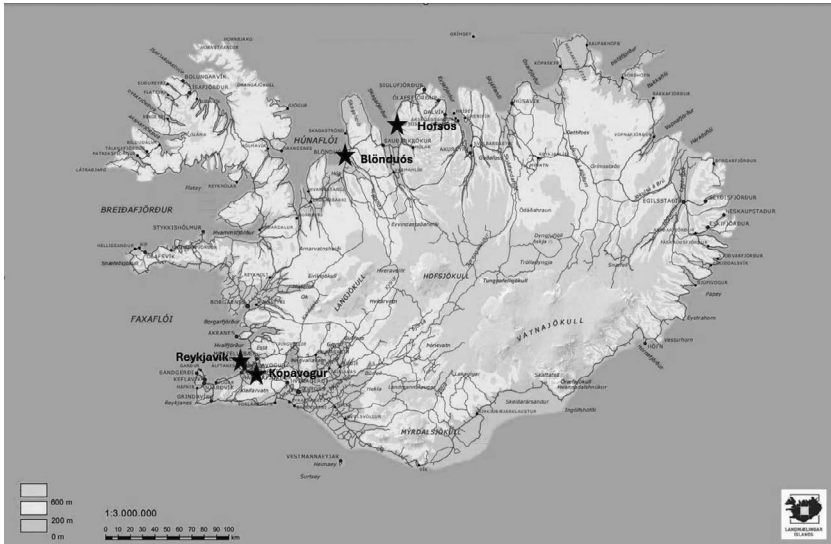


Figure 1.2 Map of Iceland

Source: National Land Survey of Iceland.

Notes: Map of Iceland showing Hofsós, Blönduós, Reykjavík, and Kópavogur

an opportunity to analyze these changes and how effective they were in the life experience of a person like her.

At the time when Bíbí was growing up, attitudes were grounded in eugenics, genetics, and medical science. The ideas of medical science were dominant: disabled people were viewed as patients, and the main emphasis was on changing or curing them. These ideas led to disabled individuals and other marginalized groups being excluded and isolated from social participation. Eugenics played a significant role in the framing of disabled people, especially women and girls, as a threat to the purity of the gene pool.<sup>4</sup> Such attitudes led to the presence of a disabled individual in a family becoming a source of grief for all. To have a disabled child was perceived as shameful; there was a societal silence about them, and it was not uncommon for them to be either hidden and isolated in their homes, as was the case with Bíbí, or sent to institutions.<sup>5</sup>

The viewpoints of eugenics and medical science led to an isolationist policy in the affairs of disabled individuals, and 24-hour institutions were established worldwide to “store” these individuals. The first legislation on services for mentally disabled people and their families in Iceland, the Act on Institutions for “feeble-minded” (Icelandic *Lög um fávítahæli*), was enacted by the Alþingi (parliament) in 1936. Although the Act was intended

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to improve the care of the “mentally deficient” or “feeble-minded,” all services were to be provided in an institutional setting. No provision was made for public services for disabled people and their families in their local communities or homes. Experts and physicians pressured parents to send their disabled children to institutions, and Bíbí’s story reveals that several attempts were made to place her in the Kópavogur Institution for people with intellectual disabilities, but she successfully resisted. Despite the fact that she lived in a home for the elderly – in the geriatric department of *Héraðshælið* in Blönduós – during her adult years, she saw that as a much better option than the Kópavogur Institution. Bíbí, like many others, realized that an institution for the “mentally deficient” or “feeble-minded,” as they were called, was not a good option, and subsequent Icelandic and international research has shown that children and adults often faced abuse and poor treatment in such institutions. Under the Act on Institutions, “feeble-minded” education and a nurturing environment were to be provided in such institutions, but in practice, they were not delivered.<sup>6</sup> The aforementioned ideas about disabled people gave rise to this group being seen as victims, or dangerous people, flawed or sick, asexual or with an unusually strong sexual drive – and as eternal children, dependent on others.<sup>7</sup>

Other ideas that emerged in the 20th century have had a significant impact on attitudes and services for disabled people. The 1970s and 1980s saw a great upheaval in the Western world: the hippie era was in full swing, the women’s movement gained momentum, and various marginalized groups grew more vocal. This led to extensive changes in welfare systems in the West and the East, which enhanced the quality of life for the general public and created a discussion about the status and rights of marginalized groups, including disabled people. Powerful disability rights movements emerged that fought vigorously for human rights and the closure of institutions.<sup>8</sup>

In Scandinavia at that time, ideas emerged that have been associated with a normal life and social participation, or *normalization*, which later had a significant impact on the status of disabled people, especially those with intellectual disabilities. Community leaders among disabled people advocated for the vision of closing down institutions and demanded that people with disabilities should enjoy the same lifestyle and conditions as people without disabilities. In 1979 new legislation was introduced regarding assistance to people with intellectual disabilities, which may be seen as milestone legislation in Iceland, as for the first time provision was made for services outside institutions and for communal living among the general population.<sup>9</sup>

The Act also stipulated the right of people with developmental disabilities to general services. But it was only with the enactment in 1992 of

legislation on matters affecting people with disabilities, which mandated the full right of disabled people to general services from local authorities, encompassing education, healthcare, and social services, that this became a reality.<sup>10</sup> This Act was in effect during the last years of Bíbí's life. Under the law, Bíbí had little right to social support until the last 15–20 years of her life. It is noteworthy that around the same time as ideas about normal living and social participation were taking root in Iceland, Bíbí moved from the old people's home to live independently, as she herself termed it, in 1974.

## **The Book**

Historical sources such as Bíbí's are rarities, both in the international context and in Iceland. Her autobiography gives unique insights into the lived experience of a person who was marginalized throughout her life and lived for most of her life in two different local communities. Her position was complex, reflecting the zeitgeist and the impact of new trends in society regarding attitudes toward disability.

The study of Bíbí's autobiography and other historical sources she created offers contributions to both theory and practice. Through history, the discussion of intellectual disability has lacked theoretical underpinnings and primarily focused on disability policy and social reform. This study will connect the fields of critical disability studies<sup>11</sup> and microhistory, thus providing a new way of critical thinking about disability.

People with intellectual disabilities have lacked a voice in history and still lack authority over their lives and experiences.<sup>12</sup> This study will focus on the perspectives and understanding of a woman with a disability, which allows us to explore and express her experiences and reflections on her life. Expanding knowledge of the lives of people with intellectual disabilities based on their own perspectives provides important information for the wider society as well as carers, professionals, and policymakers, making it possible to learn from history and improve policy and practice to meet the wishes of people with intellectual disabilities.

Bíbí's life had many manifestations, which will be researched in this book. As mentioned before, at a young age, she was placed in an institution for the elderly in a nearby town, but nonetheless, she eventually gained some freedom to live her own life and have a few friends, which was of great value to her. The study will delve into these factors: material culture in Bíbí's life, such as her gardening: she made a garden just outside the town, which she cultivated for years. Bíbí also had a considerable doll collection, which she cherished and donated to the National Museum of Iceland at the end of her life.<sup>13</sup> Both of these aspects of her life will be studied, as well as her book collection. The autobiography itself will be at the

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center stage, and we will look at it, for example, as a material reality. Her writing and style were such that she traced over each letter multiple times, and hence the work acquired a certain three-dimensionality. Her narrative and the textual environment, as well as the poetry she created along with her diaries, will be studied.

We will also explore her friendship with several individuals with whom she had considerable contact, and we will seek to map her communication network. With the objective of deepening and furthering our understanding of BÍBÍ's story, part of the study is defined as inclusive research. We enlisted the assistance of four individuals with disabilities to analyze BÍBÍ's story in collaboration with the researchers. By exploring the perspective of women with disabilities regarding BÍBÍ's story, deeper knowledge and understanding of her life and circumstances were attained.<sup>14</sup> In this way, we were able to elicit the group's peer review of BÍBÍ's story; we found out that these women with disabilities were better able to put themselves in BÍBÍ's place and grasp her circumstances than academics without disabilities.

Finally, the research will hopefully contribute to the understanding of the complex historical, social, and cultural factors that interact and have shaped the lives and afterlives of people with intellectual disabilities. What makes BÍBÍ's story unusual is precisely her unmediated relationship with the outside world through her autobiography and other historical sources. Within them, we find her own private world. Access to that world is, in our view, best ensured by bringing together disability studies and microhistory. In that way, we believe that we have managed to focus on the subject in an effective manner. This, one of the principal objectives of this study was to develop this relationship between the two disciplines and demonstrate how they can work together in an accessible manner. Through this rendezvous of the two approaches, we are convinced that it will be possible to delve far deeper into the history of people with disabilities. Traditional text documents are thus not all that will be on our agenda; we will also seek out all possible connections with BÍBÍ's life that are likely to throw light on her world, mindset, and circumstances.

This book is based on an analytical endeavor to delve into the astonishing life of BÍBÍ in Berlin. Even though our book is scholarly, we also tell an extraordinary story. To enrich our readers' understanding and allow them to experience BÍBÍ's unique voice, we conclude each chapter with an excerpt from her autobiography, inviting them to explore her expressions firsthand and reflect without our interpretative lens.

### **The State of the Art – Historical Background**

The history of intellectual disabilities in the 20th century is largely a story of discrimination and social exclusion. In historical public records, people

with intellectual disabilities were, for the most part, presented as abnormal and inferior.<sup>15</sup> This is the narrative that dominates the history of intellectual disability. A *grand narrative* is commonly defined as a story that unifies and totalizes the world and justifies a culture's power and structures.<sup>16</sup>

It is a story that is authoritative, accepted, and supported by the dominant institutions in society, and as such, it is the main force in determining our self-understanding and our comprehension of others.<sup>17</sup> The eugenics movement and medical understanding of disability are the grand narratives that have played a crucial role in constructing societal views and stereotypical understandings of people with intellectual disabilities.<sup>18</sup> The eugenics movement argued that "feeble-mindedness" was hereditary and "mental defectives" were seen as a threat to society due to their uncontrollable urges and degenerate characteristics. The "'professional community,' armed with scientific data from heredity studies, aggressively pursued such restrictive measures as controlled marriages, sterilization, and segregation."<sup>19</sup> In this context, it has been pointed out that attitudes toward people with intellectual disabilities were, to some degree, gendered. For example, more women than men with intellectual disabilities were institutionalized, and women were the vast majority of those subjected to involuntary sterilization.<sup>20</sup>

As a result of the medical understanding of disability, people with disabilities have often been characterized as tragic or silent victims: sexless, eternal children, or subjects for doctors' and specialists' remedies such as cure, care, or segregation.<sup>21</sup> It has also been acknowledged that women and girls have been victims of diverse violence throughout the 20th century, and they have had more limited access to education and the labor market than men with disabilities and women without disabilities.<sup>22</sup>

As a consequence of the attitudes described above, it was seen as shameful for parents to have a child with disabilities, lending support to prevailing professional opinions that institutionalization was in the best interest of all concerned. Despite this, many children grew up with their parents and siblings, even though education was not available, nor was there any other social support or social services.<sup>23</sup>

The first legislation concerning people with intellectual disabilities in Iceland was passed in 1936: The Act on Institutions for the Feeble-Minded.<sup>24</sup> The Act defined the legal framework for the first Icelandic institution of its kind. The policy of founding institutions was intended to improve people's living conditions and provide education. It later transpired that children and adults were subjected to inhumane treatment and oppressive conditions at the institutions, while education or any other form of meaningful activity was rarely provided.<sup>25</sup>

After the 1970s, the ideology of normalization replaced ideas of segregation and institutionalization, calling for a "normal life" for people



with intellectual disabilities and advocating for their right to take part in regular community life.<sup>26</sup> The principle of normalization has been the basis for legislation in most western countries since the 1970s, including Iceland, and has brought significant improvements in the lives of people with intellectual disabilities. Although all the countries saw important reforms following the introduction of normalization, large groups are still in segregated settings. Also, research suggests that people still lack power, and decisions about their daily lives are often made by carers and professionals.<sup>27</sup> Throughout history, people with intellectual disabilities have lacked voice, authority, and control over their lives. Not until recent times have they been acknowledged as valuable contributors to the history and discussion of intellectual disabilities.<sup>28</sup> Since the 1990s, there has been an increasing commitment to averting this trend and engaging people with intellectual disabilities in many forms of biographical and life-history story work.<sup>29</sup>

The pioneering work of US scholars Edgerton (1967) in listening to the views of people with intellectual disabilities and that of Bogdan and Taylor (1982) in giving validity to people's life stories, paved the way; they were of great importance and contributed greatly to changing attitudes and to disability studies. The life stories of people with intellectual disabilities have flourished since the 1990s, especially in the United Kingdom.<sup>30</sup> Recently, some significant international anthologies have also been published.<sup>31</sup>

In Iceland, biographical and life story work with people with intellectual disabilities is a relatively new research area. Thus, several life stories of Icelandic people with intellectual disabilities have been published in international anthologies. Some Icelandic life stories of people with intellectual disabilities have also been published as part of doctoral theses.<sup>32</sup> Thus, the majority of the life stories mentioned above (international and Icelandic) have been carried out in cooperation between researchers and people with intellectual disabilities. Autobiographies written by people with intellectual disabilities are rarely found, though with some exceptions.<sup>33</sup>

Most of the autobiographies and life stories mentioned above have provided accounts of a range of societal discrimination and abuse, often in institutions where individuals have been subject to inhumane treatment and oppressive conditions. At the same time, a life history can also be a form of resistance, a counter-narrative told in opposition to the dehumanizing conditions and portrayals of people with intellectual disabilities as helpless victims living tragic lives.<sup>34</sup> Hence, autobiographies similar to Bibí's are rarities, both in the international context and in Iceland. Bibí's story provides unique insights into the lived experience of a person who was marginalized throughout her life, living all her life in two small communities in northern Iceland.

## Methodology

Bíbí's autobiography and other source material that she created are analyzed by focusing on two research disciplines: critical disability studies and the methods of microhistory. A feminist intersectionality framework is also used to analyze Bíbí's story, focusing on how disability, class, and gender intersect, leading to multiple forms of discrimination in her life. In addition, qualitative methods were used in collecting and analyzing the data. This combination of methods is new and unusual, but we are convinced that the methods of microhistory and critical disability studies will give us an excellent opportunity to deal with the life of Bíbí in Berlín from a very effective perspective. The principal methods and approaches of the study are described below:

Bíbí's extraordinary document is the central feature of our study, and we have studied it and Bíbí's life in as diverse a manner as possible. We have applied the *methods of microhistory* to egodocuments, or autobiographical material such as the work of Bíbí. We have employed a special methodology, which one of the authors of this book, Sigurður Gylfi Magnússon, calls the "singularization of history." This approach, which he has been developing over the last 20 years against the background of microhistorical ideology, is aimed precisely at defining the opportunities offered by sources like egodocuments to talk about the past in as varied a way as possible, often, and preferably, outside the received channels of the grand narratives.<sup>35</sup> The analysis centers firmly on the "texts" themselves (narratives, illustrations, objects, etc.): their creation and context within the events they describe or situations they reflect.<sup>36</sup>

The approach we have adopted in this research project is based in part on a "living" research model that Sigurður Gylfi has called "the textual environment," which incorporates a detailed analysis of all aspects of the space in which the "text" was produced, maintained, used, and disseminated.<sup>37</sup> By "living," we mean that we consider any event or situation that influences the form of the text, illustration, or object and the analytical processes evidenced in its creation. The thinking behind the "textual environment," as Sigurður Gylfi has developed the idea in recent writings, is to draw scholars' attention both to the content of the source (the textual space) and to its encompassing environment, the meanings and connections that constitute the textual whole. The "textual environment" is the totality of the space that makes the "text" (of whatever type) the medium that we find evidenced in its content and outer form.<sup>38</sup> The primary question here is: Is a "text" merely the "record" of events that took place at some time in the past, or can it have a wider reference in the present? This approach is particularly interesting in the case of Bíbí, since the

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source material related to her “travels through time,” so to speak, and its meaning differs over the period in question.

The interrelationship between our sources and the past, and particularly the sources’ muted echo of historical time, means that it is important to approach the “textual environment” in a unified and holistic manner so as to avoid rupturing or fragmenting the inherent context of the “text.” American historian Luise White uses a similar approach in *Speaking with Vampires*, where she attempts to come to terms with the history of people in Africa who, in the vast majority of cases, have no written sources to record their pasts.<sup>39</sup> Here, “texts” of many kinds become a force in people’s lives, directing how their users think about and interpret the past and their history. The distinction between public sources and oral sources, between sources that are part of the human landscape of society – the material culture – and written sources in whatever form, breaks down; what matters is how the sources are used in time and space.<sup>40</sup> The rationale behind this approach lies in the realization that sources are not just “pieces of information,” but rather phenomena that are “alive”: they are used to explain the background to specific circumstances in ways that are always contingent on the thinking and ideas of the people that talk about them. The critical disability approach is very sensitive to this complicated “dialogue” between the individual, the source material, and society at large, all variables go through new understanding and meaning from one time to the next. Bíbí’s story enables us to explore shifting notions of disablism and ableism over time, in a specific geographical context.<sup>41</sup>

The material of this book is certainly discussed “broad-brush” in the light of the grand narrative of social development in the 20th century, but with special consideration of discrete examples – Bíbí’s autobiographical material – taken for detailed study in the spirit of microhistorical ideology and critical disability approach.<sup>42</sup> Through this twin-faceted approach, we attempted to create a synthesis of the area of research while deepening it by focusing specifically on restricted aspects, with a concomitant depreciation of the importance of grand narratives in historical explanation. Recent work on the history of emotions, exemplifying the approach envisaged here, includes writings by Sigurður Gylfi and others.<sup>43</sup>

Earlier work on the history of emotions was deeply influenced by modernization theory and frequently attempted to define and characterize the emotional cultures of entire countries and even continents – something that would, for example, go hand in hand with the success story of the medical profession and greatly affect ideas about intellectual disability.<sup>44</sup>

In 2002, American scholar Barbara H. Rosenwein published an influential article in which she reduced the scale, subjecting individual small societies to minute analysis. Every society, Rosenwein concluded in a 2006 book, has its own special peculiarities that are fluid and “alive,” constantly

changing according to the individuals in question and the circumstances in which they live.<sup>45</sup> We have used the model developed by Rosenwein to map out this world of BÍbí in Berlín.

There are obvious gains to be had from exploiting the strengths of the microhistorical method, an approach whose practical applications have been experimented with for many years by us who are part of this research project and with which we now feel fully conversant. We subjected the material to a rigorous microhistorical analysis with a view to creating a synthesis of the methodologies of the “textual environment” and “the singularization of history,” each being a kind of kickoff from the microhistorical method, and now with the aid of the focus of critical disability studies.<sup>46</sup> Microhistorical methodology, by its very nature, demands the creation of ad hoc approaches tailored to the needs of individual projects, and we shall attempt to provide a precise analysis of its possibilities in the context of this particular study.<sup>47</sup> We argue that the work that goes into this book will be of genuine significance, both for the development of microhistory in the international arena and for the understanding of critical disability studies.

The “textual environment,” “the singularization of history,” and “critical disability studies” may, with some justice, be said to derive ultimately from post-structural analytical methods. Behind these methodological approaches lies the idea that each manuscript, each text, is a forum for expression with multiple layers of meaning that it is important to deconstruct and analyze, as demonstrated so clearly in the material from BÍbí.

This microhistorical approach exists in many variants. Some microhistorians are more determined than others in contextualizing their studies, although most see it as one of the principal qualities of this historical approach.<sup>48</sup> Few, however, have completely rejected the idea that it may be desirable not to contextualize, as is the approach in the “singularization of history” model. By applying the “textual environment” research model, we go even further than was originally intended by examining each source in the greatest possible detail – exploring their composition and examining them with the greatest possible accuracy – with the aim of gaining an understanding of the story they tell (its narration) and how they can be used to understand the past or, more precisely, to construct the past, as will be discussed in the next chapter. The scholarly union with critical disability studies has made this focus more appealing than ever before, as scholars using that methodology put all their intellectual energy into a detailed understanding of the subject at hand.<sup>49</sup>

That approach has led to such diverse subjects of research as material culture and the history of emotions, and in this research project, we seek to counterpose these two phenomena in the context of the everyday life experience of BÍbí in Berlín. Both offer an opportunity for an interesting

application of the research models – the singularization of history, the textual environment, and critical disability studies – where we seek to direct the focus onto the subject *per se*. The material culture is not simply an accumulation comprising the total, “all” material surrounding our lives: in fact, each individual object has its own story and meaning; its own narration, which is susceptible to analysis. This is certainly true of the source material BÍbí created. The same applies to the role of emotions in human life: material relating to them, such as egodocuments, provides the opportunity to delve deep into the human psyche and throw light on specific aspects of human existence as told by those who took part in the event.<sup>50</sup>

In this research, we have placed great emphasis on minimizing all contextualization vis-à-vis the environment, limiting it to the immediate environment of the subject, because we do want to draw a clear line between the past and the history we decide to tell about that past. That is only possible if we are willing to reject the grand contextualization that is the benchmark of most scholarly works in the humanities and social sciences. As soon as a scholar loses sight of local knowledge, in whatever form it is manifested, they will start to rely upon something else, unrelated to the subject; we may call this the structural formation of the official discourse of the historical discipline.<sup>51</sup>

As has been mentioned before in this chapter, we turn our focus inwards to explore in as much detail as possible all data relating to BÍbí in Berlín. Such an approach offers scholars an opportunity to seek out new knowledge and unknown phenomena in human life and throw an unexpected light on them. Their narration is, of course, their own creation, but the foundation of that creation is based on the contemporary narrative found in the historical sources. The distinction between the past and history is thus acknowledged, but at the same time, an attempt is made to gain a new insight into former times by deconstruction of historical sources to the fullest degree. When microhistorians have the courage of their convictions to stand by their micro-approach, as we do, new opportunities open up for analysis, as has been shown and proven in the work of many microhistorians all over the world.

We have to remember that the task of critical disability studies is to analyze disability as a cultural, historical, social, and political phenomenon.<sup>52</sup> Like traditional disability studies, the discipline challenges approaches that pathologize physical, mental, and sensory differences as being in need of correction and instead advocates for both accommodation and equality for disabled people in all areas of life. Additionally, critical disability studies actively seek alliances and have produced work in conversation with other key areas of critical thought, for example, critical race theory and critical feminist theory. Critical disability studies, like other critical theories, are invested in bringing about social change. The method is used both

to describe the socio-political constructions of disability and to track the impacts of these constructions on marginalized people. Critical disability studies therefore refer to lived experiences and attempt to transform the circumstances under which oppressed people live through critical intersectional analysis.<sup>53</sup>

Intersectionality is a definition used to describe the experiences of marginalized people in terms of multiple factors. It acknowledges that systems of gender, ability, race, age, and social class intersect and influence wider power relations and personal experience. From the intersectionality point of view, disability is not considered in isolation from other social categories such as race, social class, gender, and others' power dynamics. Thus, it becomes more apparent that different social categories and oppressions work together in producing injustice.<sup>54</sup>

Critical disability studies are significantly aimed at analyzing ableism.<sup>55</sup> Ableism in the context of disability means that certain physical, cognitive, sensory, or other types of abilities are preferred, and people who have differing abilities are considered impaired and different. Ableism is discrimination on the basis of ability and a network of beliefs, processes, and practices that produces a particular kind of self and body that is projected as perfect and therefore essential and fully human. Such ableist views have been used to legitimize the unequal treatment of disabled people. In ableist societies, disabled people are viewed as less valuable, or even less than humans. The eugenics movement of the early 20th century may be considered an example of widespread ableism.

Qualitative methods are used to collect and analyze data, both in historical and disability studies. Qualitative research methodology refers to descriptive data, such as written documents and interviews. Qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study phenomena in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research assumes that everyone has a story to tell and that all perspectives are equally important.<sup>56</sup>

In this research, the use of qualitative methods is twofold: Firstly, qualitative interviews have been carried out with 21 of Bibí's relatives and contemporaries. Secondly, part of the research is categorized as inclusive research.<sup>57</sup> Inclusive research has its roots in qualitative participatory research and feminist research, which fundamentally developed in the 1970s from an awareness that much research had been gender biased and was undertaken from the perspectives of men's experiences, leading to only a partial understanding of social life.<sup>58</sup> Inclusive research allows people with intellectual disabilities to take an active part as collaborators in the research process, and not passive research

subjects.<sup>59</sup> In this research, four women with intellectual disabilities have been active collaborators in analyzing BÍBÍ's story over a period of four months.

By integrating these methodologies into our book, we were able to treat the selected "texts" as cultural artifacts in new and challenging ways. This approach to our research project was fully in line with the ways in which our ideas have been developing in recent years, and we endeavored to build on these ideas as our research progressed. We aimed from the beginning to make a bridge between these three intellectual approaches – critical disability studies, qualitative research, and microhistory – because we were convinced it would open up a new and exciting intellectual challenge in the future. We argue that this development came into being in the book itself.

### **Ethical Challenges**

Various ethical issues arose during the research process, which the research team discussed in detail. Firstly, the following question arose: How can we interpret and address BÍBÍ's autobiography with respect for her as a person and express what was most important to her? It is beyond question that BÍBÍ wanted her autobiography published, and she tried by various means to make that happen before she died. In all our discussion and interpretation of the autobiography, we strove to display respect for BÍBÍ and her identity, although we could not be sure what BÍBÍ would have thought of our interpretation. For that reason, we kept to her own text with all possible accuracy.

Secondly, one of the major ethical challenges of the study of BÍBÍ was the matter of finding a way to safeguard BÍBÍ's surviving relatives and treat them with respect, especially those who were interviewed. In her autobiography, BÍBÍ spared neither her relatives nor the people of Hofsós and Blönduós; she made fun of some, ridiculed others, and told tales about them. She also wrote about various embarrassing events that were uncomfortable for some of her relatives, about which there had been a conspiracy of silence.

During the research process, we got to know some of BÍBÍ's relatives and visited them; in her autobiography, BÍBÍ discusses various sensitive issues relating to these individuals and/or their families. They provided us with invaluable information about BÍBÍ's life and personality. In the interviews, it transpired that some of BÍBÍ's closest relatives had, after hearing about her autobiography, been quite worried about what BÍBÍ might have written about them and their immediate family. They feared that BÍBÍ's writings might bring disgrace on them and their families, as BÍBÍ had been known to be a mischief-maker.

General ethical guidelines for research provide that efforts be made to safeguard participants from any harm or risk arising from research participation. Examples of possible participant risks include physical harm, loss of privacy, emotional distress, or embarrassment.<sup>60</sup> Anonymity and confidentiality are also important ethical concerns, not least in a small society such as Iceland, where people can easily be identified.<sup>61</sup> It was thus a considerable ethical challenge to be guided on the one hand by these rules and on the other to keep faith with BÍBÍ's autobiography and what she wanted to say. Our conclusion was that we would not name BÍBÍ's living relatives in cases of sensitive events or stories, although she does so in the book. When the autobiography is quoted directly, names are included, since this is BÍBÍ's intellectual property, which we were unwilling to censor, as mentioned above.

Thirdly, we considered whether BÍBÍ's narrative could be regarded as unconditionally reliable, as she often passes harsh judgments on her nearest relatives: her father, mother, and other relations, as mentioned above. This conundrum was not easily resolved, but we tended to believe BÍBÍ's narrative, except, of course, where other evidence revealed during the research process disproved her account. For example, we were informed by many people we spoke to that BÍBÍ's father, Kristján, had been a hard man and sometimes spiteful. BÍBÍ certainly said what she thought of him, but on occasion she wrote about him with affection. In other words, we discovered that BÍBÍ had been fair in her verdicts, though admittedly often somewhat judgmental.

Here we discuss examples of ethical issues raised by our study of this remarkable woman, many of which relate to issues that scholars grapple with on a daily basis in their research, while others were more specific to a life – BÍBÍ's daily life – that is almost unparalleled.<sup>62</sup>

### **Interdisciplinary Ways of Doing Research: A New Approach**

The overall aim of this book is to explore BÍBÍ's source material and identify how various historical, social, and cultural factors influenced her life and circumstances. More specifically, the aims of the book are as follows:

- 1 To shed light on the hidden history of people with intellectual disabilities, especially girls and women in Iceland born in the first half of the 20th century.
- 2 To explore how social class, disability, gender, and emotional communities intersect and influence BÍBÍ's life.
- 3 To explore how the scientific knowledge and dominant ideology about people with intellectual disabilities – the grand narrative of the



accomplishments of the medical profession – influenced and shaped BÍbÍ’s life and circumstances.

- 4 To reflect on how BÍbÍ’s historical sources appear as a counter-narrative – counter-archive – that resists negative beliefs and stereotypes of people with intellectual disabilities.
- 5 To explore the intellectual opportunity that is to be found in the connection between critical disability studies and microhistory; a new and exciting theoretical and conceptual framework spanning two innovative academic disciplines.
- 6 To explore how people with intellectual disabilities experience the history of disability through BÍbÍ’s story by adopting an inclusive approach for a peer review process.
- 7 To explore and contextualize BÍbÍ’s material and cultural heritage by examining her doll collection, her garden, the manuscript of her autobiography, the poetry she wrote, her diaries, the book collection, the layout of housing in four different places, as well as illustrations from her life. It will focus on her own *agency* in creating her life story, how she maintained the narrative, and how/if it was preserved and managed after she died.

All this historical material that is part of BÍbÍ’s legacy gave us an opportunity to build up a new approach between critical disability studies and the methods of microhistory. That was made possible by the exceptionally rich source material that is part of BÍbÍ’s life.

We do not rely solely on the source material that BÍbÍ created, because public records also have a story to tell. From the period known as the “Haze Famine” (*Móðuharðindi*, 1783–85) until the early 1900s, most public supervision was under the authority of clergymen, district administrative officers, and county magistrates. This authority can be divided into two realms: spiritual and secular. Notably, the spiritual authority provided primary education and prepared individuals for confirmation at the age of 14 – the critical ritual of entering adulthood. On the other hand, the secular authority was responsible for providing minimal support to those unable to work and sustain themselves through the distribution of poor relief. The combination of limited education, closely tied to confirmation, and the ability to work resulted in the marginalization of certain individuals.

Public sources were created within administrative frameworks to collect and preserve information about the population, strengthening governance and providing necessary facts. When using sources such as censuses, church records, parish registers, and medical reports, it is essential to understand the information’s underlying assumptions and intended scope. These sources are limited to answering specific questions outlined in their assumptions. Each entry in these source categories is attributed to a

recorder who held a specific office and role. This context should be taken into account when utilizing these source categories.

As mentioned earlier, the records produced by the authorities have various origins. They include censuses, church records, parish registers, and annual reports detailing the state of affairs submitted by subordinates to their supervisors. Each record reflects the perspective of its author. For instance, in describing his congregation, a clergyman would use a different language from that employed by district administrative officers or other secular authorities. Nonetheless, by systematically analyzing contemporaneous accounts focusing on individuals with disabilities, it is possible to uncover traces and indications of disabled individuals within any society.<sup>63</sup>

By employing the critical lens of disability studies and utilizing micro-historical methods, it has been possible to unravel the complexities of Bíbí's life. The primary sources in this investigation stem from the vicar in Hof Parish, encompassing both church records and parish registers. Additionally, regular censuses conducted every ten years provide valuable insights into the community structure of the era.

We obtained permission from the National Archives of Iceland to investigate Bíbí's medical records from the home for the elderly.<sup>64</sup> These records pertain to her admission to the old age home, her stay at the National Hospital in Reykjavík (*Landspítali Íslands*), and the final years following the deterioration of her health. Medical records are sensitive documents subject to the same legal principles as other public records. It is essential to consider the authorship of these records, the roles and relationships of the individuals involved with Bíbí, and most importantly, their creation dates. Through Bíbí's medical records, spanning over forty years, one can observe changes in the assessment of the public's perception of vulnerable and disabled individuals.

Atli Þór Kristinsson wrote an MA thesis about young people in homes for the elderly in Iceland in the 20th century, in connection with our research project. He gained access to medical records and important information about age distribution in Iceland's homes for the elderly.<sup>65</sup> His findings helped us to understand Bíbí's situation much better and what her life was like in comparison with other young people in similar institutions.

Expanding knowledge of the lives of disabled people based on their own perspectives is an unusual opportunity and provides important information for society at large: carers, professionals, and policymakers. These egodocuments – Bíbí's autobiographical material – make it possible to explore the desire and lust for life of a person who was kept hidden from mainstream society. Hopefully, our book will contribute to the understanding of the complex factors that have constructed and shaped disability and influenced the lives of people with disabilities – not only Bíbí's everyday life but also the lives of thousands of individuals in her position



*Figure 1.3* The cottage at Berlín in the early 20th century

*Source:* Photographer unknown: Regional Archives of Skagafjörður – the collection of Jakob Einarsson.

*Notes:* Before Bíbí and her parents moved into Berlín, probably in 1929, it was the home of a certain Eiríkur and his wife Ingunn, who are pictured here with their sons. The couple were the grandparents of Alda Kristín Jóhannsdóttir, Bíbí's girlhood friend and soulmate. One of the boys is Alda's father, Jóhann. The house had an area of only 15 m<sup>2</sup>, with a small basement and loft. It accommodated a family of four in very cramped conditions.

all over the world. What makes Bíbí's history extraordinary is precisely the direct connection to her world through her autobiographical material and other important sources connected to her and how society at large reacted to her life story.

### How It All Happened

In the early 1980s, Bíbí wrote her autobiography, all in capital letters, in 19 exercise books, totaling 1,200 pages, or about 145,000 words. The original manuscript is now in the keeping of the Manuscript Department of the National and University Library of Iceland. Haraldur Jóhannsson, a childhood neighbor and the brother of her friend Alda, first transcribed the text into digital form, probably around 1990. In 1987 Bíbí had asked him to seek a publisher for the book, and he had contacted a

friend in publishing, Þorvaldur Kristinsson. He judged that it would be difficult to publish the autobiography, but he nonetheless realized that this was a manuscript unparalleled in Iceland and perhaps even internationally. Time passed, and many years later, Þorvaldur, who had a copy of Haraldur's transcript, saw a possibility and passed it on to his friend Guðrún Valgerður Stefánsdóttir, Professor of Disability Studies; he believed that she might be able to find a way to promote the work. At that time, 25 years had passed since Þorvaldur had first heard about this remarkable manuscript.

Guðrún soon started working in collaboration with the authors of this book, Sigurður Gylfi Magnússon, Professor of History, and Sólveig Ólafsdóttir, then a doctoral student, within a major research project on the theme *Disability before Disability*; a decision was made immediately to make a thorough study of Bíbí's manuscript and story. In 2020 the authors applied for funding for a research project from the Icelandic Research Fund, administered by the Icelandic Centre for Research (Rannís); they were allocated a three-year research grant to study Bíbí's life exhaustively and explore as many elements as possible in all imaginable detail.

Within the framework of the research project, plans were made for the ambitious project of publishing the autobiography in Icelandic, verbatim, and letter for letter. This required an extensive comparison between Haraldur's transcript, in which he had made considerable revisions according to his own taste – and Bíbí's original text. Haraldur inserted, for instance, new headings and also omitted parts of the manuscript he regarded as unfit for publication. The autobiography as published in the Icelandic edition follows the original text as precisely as possible, though with minor corrections in cases of obvious slips of the pen.

Bíbí wrote her texts mostly in capital letters, but this has been changed to comply with normal rules of orthography. That task was carried out by Atli Þór Kristinsson, an MA student in history at the University of Iceland, under our guidance, and he made an important contribution through that demanding task. It is safe to say that the book attracted great attention in Iceland; everywhere that it was promoted, it received extensive coverage, as will be discussed further later in the book.

The work involved in the Icelandic edition, which was published in the series *Anthology of Icelandic Popular Culture (Sýnisbók íslenskrar alþýðumeningar)*, was based on a detailed examination of the content of the manuscript; that work was primarily carried out by Guðrún Valgerður, who also contributed an introduction about Bíbí's life and position in society.<sup>66</sup> The intention was that the published manuscript would prove useful to us, the authors of this book, in analyzing the many elements of Bíbí's story and the people around her in the research that is presented in this volume.

## 22 *Introduction*

We considered, naturally, how best to carry out this work and how best to present BÍBÍ's text. Our main idea was primarily to be faithful to BÍBÍ's text and to publish it without forcing our own ideology onto her world of ideas. We wanted to try to enable readers of the autobiography to get as close as possible to BÍBÍ through this edition. It should be pointed out that BÍBÍ's spelling was not correct according to modern rules of Icelandic orthography, but all that she writes in her own way is entirely comprehensible.

This story is told here in order to explain how the manuscript got into book form. Most important, of course, is that BÍBÍ herself was very keen to have the manuscript published, as stated above. In addition, people featured in the book who were close to BÍBÍ and wished her well.

When we, who did not know BÍBÍ, received the manuscript, we focused on carrying out the task in such a way as to be a credit to BÍBÍ and to ourselves. It was obvious to us that the manuscript opens up an unusual perspective on Icelandic society in the 20th century – and, in fact, on the status of people with disabilities in general, internationally. Without doubt, the work is unique in the world, and it is vital that the ethical element should be clear and unambiguously formulated.

Let us give BÍBÍ the last word regarding the manuscript itself and the reasons why she wrote her story: “I want to say a little about how it came about that I've written about the people who are mentioned in the book. The people I have got to know here, either at the home or otherwise. I don't like the idea of their being forgotten, I want to commemorate them in some way. I am grateful to these people for our good acquaintanceship, it's not certain that all these contemporaries can read this, but hopefully some of them can, it may not get into print for a while.”

It is important to attempt to bring out the reasons why BÍBÍ, who assuredly lived on the margins of society all her life, felt it was right to sit down, without a word to anyone, to tell her story. What was it in the culture of the time that led to her seeing this as the right thing for her to do? It must be reiterated that BÍBÍ undertook her task without many people knowing what she was doing; it was her secret, and indeed, few people were even aware that she could read and write.

It is naturally very interesting that a woman who was sidelined in society should have been able to take on the demanding task of writing her autobiography. It is no small undertaking, requiring concentration, perseverance, and clear thinking. But that was not all BÍBÍ did. As we have stated earlier, she collected dolls, made a beautiful garden from almost nothing, at some distance from her home in Blönduós, and collected books. In addition, she kept diaries and wrote a collection of verse preserved in a 100-page book – a sort of timeline of her first ten years in Blönduós. All these sources are, to say the least, highly unusual and provide good insight into the mind of the individual. The quantity of the sources is, in short,

incredible. The situation is made even more unbelievable because BÍBÍ was a woman whose life was spent outside the ordinary lives of others. In her way, she was completely alone.

In the next chapter, we will delve into these archives with the aim of telling their story and placing them in the context of the lives and works of people in the 20th century. In that way, we will achieve a better understanding of how BÍBÍ dealt with the obstacles she faced all her life. BÍBÍ had *agency* in her life, and in a sense, we may say that she created counter-archives whose primary objective was to expose the injustice in the world, the injustice that she struggled with in various forms all her life. We tend toward the conclusion that she succeeded better than most others we have studied. BÍBÍ's story is thus unique, and at the same time, she offers an unusual opportunity to address 20th-century society in Iceland and elsewhere in the world. Due to BÍBÍ's extraordinary depiction of her life story, we get to hear about the responses of people at all stages of her life to various challenges she faced, and that opens up to us a vision of the way that all of society functioned.

### From the Autobiography – *Bíbí in Berlín*

*Who is this person?*

*“Who is this person?” you may ask. Yes, she has made the garden and fenced it in so livestock would not go in and ruin the vegetation. Is this the answer to who the person is? No, it is not. The one who made the garden and the one who wrote the book is the same one. That is the case.<sup>67</sup>*

*Books*

*There were various rumors going around after I arrived at Hælið, one of which was that I was not supposed to be literate or able to write. I was so offended and angry about this, I felt that such a great shame was being done to my parents with this, because even though I did not attend elementary school, I was still made to learn. Well, I was made to learn to read and write, like other children at that time.*

*I had my own library too, that was because the books at the library at Hælið, they were not to my taste, so much was certain. I think people thought that I did not need to own books and also the other thing, that if I had never owned a book, it would be easy to say that I was illiterate. But that is not something that can be said about people, if they own books, at least that's what I believe.<sup>68</sup>*

*Friend*

*I began writing this book when I started talking about it with my friend who has now passed away, once when I visited her, and she agreed with me and encouraged me to write it. The book is dedicated to my friend, Alda Kristin Jóhannsdóttir.<sup>69</sup>*

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## 2 The Life of BÍbÍ in Berlín as a Text Historical Sources

This chapter addresses the subject of the sources and the unusual combination they comprise. It is safe to say that the source material that BÍbÍ created is almost unparalleled; and its composition certainly offers the opportunity to consider BÍbÍ from various perspectives. The characteristic feature is that the sources provide strong evidence that BÍbÍ succeeded in taking control and dealing with her confined circumstances with admirable results. An autobiography, diaries, an annal, poetry, doll and book collections, and finally her garden are the subjects of this chapter – BÍbÍ as a counter-archive.

### The Archive

What is an archive? That is, essentially, the question at the heart of the discourse in this chapter. We have approached the archive as a phenomenon which possesses the quality of being able to tell a story – essentially, any story. By this we mean that each individual has a different sense of the archive they have in their hands. That is the origin of many egodocuments that will be discussed in this chapter. Each and every writer has some kind of archive to work from when they write their stories, their reflections on life and existence.<sup>1</sup>

Antoinette Burton, editor of *Archive Stories*, wrote in her introduction to the book, about collection and storage of sources:

Of course, archives – that is, traces of the past collected either intentionally or haphazardly as “evidence” – are by no means limited to official spaces or state repositories. They have been housed in a variety of unofficial sites since time immemorial. From the Rosetta stone to medieval tapestry to Victorian house museums to African body tattoos, scholars have been “reading” historical evidence off of any number of different archival incarnations for centuries, though the extent to which a still quite positivist contemporary

historical profession (both in the West and outside it) recognizes all such traces as legitimate archival sources is a matter of some debate.<sup>2</sup>

The archive is a reflection of some reality, which often has nothing to do with the material of which the archive apparently consists when it is examined *in toto*. This brings us to the so-called *potential history* of Ewa Domańska, which is something she, and philosopher Rosi Braidotti, argue for in their writing.<sup>3</sup> Domańska calls it *affirmative humanities*. But what is that? Domańska replies by pointing out that her understanding of the phenomenon is as follows:

An affirmative humanities is not about affirming and protecting a traditional concept of life. Instead, it is about support, empowerment, stimulating development, and constructing space for creating individual and collective identity/subjectivity; about creating potentiality (*potentia*) for actions contributing to designing futures within a framework of “sustainable development.”<sup>4</sup>

Affirmative humanities is thus a forward-looking ideology which rejects the negative and focuses on the positive in the future by abolishing old variables which we tend to use for comparison. The identifying features of affirmative humanities are thus a range of factors with which we are familiar from scholarship and science, such as to reject the egocentric human individual, that we often define as an assemblage of human and non-human persons. In other words, Domańska takes the concept to mean “knowledge of co-existence in conflict ... that is future-oriented and works to neutralise both anthropocentrism as well as eurocentrism, which, until now, have been the dominant modes of constructing knowledge about the world and humanity.”<sup>5</sup>

The method Domańska seeks to apply is grounded in “positive” reading of historical sources, and an attempt to avoid “various forms of insufficiency, such as incoherence, contradiction, logical errors and weakness of argumentation.” According to Domańska, philosopher Elizabeth Grosz maintained that this was very much in tune with a male way of reading historical sources. By pursuing research in this manner, she says, it would probably be possible to bring out the potential of any historical situation that has previously been overlooked. Grosz, however, advocates abandoning a critical approach, and she is more an advocate of “an uncritical affirmative reading,” with which Domańska does not agree. She wishes, on the contrary, to uphold all the strict standards of source criticism or information evaluation, while pursuing such studies by a positive affirmative method.

These ideas give rise to what may be termed “potential history,” a concept which we plan to use in this book and will be explained at the end of this chapter. The archive that belongs to BÍBÍ is so unusual that it calls for a different approach from what we are accustomed to. Her story is so far out on the periphery it will not be recognized as important with traditional sources that have not made room for people like BÍBÍ. Our aim is reconciliatory, as Domańska points out; it prises out of the past “unrealised potentials, with this being a condition for creating a different future.”<sup>6</sup> The key, to Domańska, is the creation of archives made up of material that is conducive to a new approach on the principles of affirmative humanities. We maintain, on the other hand, that it is possible to take “old” archives, like the one assembled by BÍBÍ, and re-read them, applying the method offered by potential history – free of the requirement to seek out something specific in the sources (as traditional history generally requires of its followers), instead approaching the entire archive as an entity which can point us toward a “positive” image of the future. As Domańska puts it, the imagination is a certain basis for potential history, “as it draws attention to the role of the imagination in knowledge-making and the legitimacy of shaping the imagination of young practitioners of historical knowledge.”<sup>7</sup> The link between the archive as we understand it and potential history is obvious; seeing archives as ways of shaping the future, not simply preserving the past, since they are ultimately about the kind of pasts we want to project into the future. The archive created by BÍBÍ in Berlín offer us that kind of approach, to set the historical arguments straight and draw out the importance of telling her story in as much detail as possible.

## The Autobiography – the Manuscript

### *The Autobiography as a Historical Phenomenon*

In *Íslensk bókmenntasaga* (History of Icelandic Literature), the late Matthías Viðar Sæmundsson, associate professor in Icelandic literature at the University of Iceland, gave an account of the content of autobiographical material in Iceland through the centuries and their relationship to comparable writings from mainland Europe.<sup>8</sup> In a sense, travel books may be said to have constituted a springboard for individuals’ self-expression, leading to the fully-formed autobiography as seen in the 19th and 20th centuries.

Firstly, we have to consider the literary forms which provided models for the biography: “The writing of biographies did not begin in earnest in Iceland until after 1700,” writes Matthías Viðar, and he continues:

... although various genres of old Icelandic literature may be classified as biographies, the trail was blazed by the Rev. Jón Halldórsson

of Hítardalur (1665–1736), writing *Biskupasögur* [Histories of Bishops], *Skólameistarasögur* [Histories of School Principals] at Skálholt 1552–1728 and *Prestasögur* [Histories of Pastors] in the diocese of Skálholt from the Reformation [in the 16<sup>th</sup> century] until 1730. Others continued to write such personal histories, but these were generally brief accounts or summaries. The most remarkable of these biographies is that of [scholar and manuscript collector] Árni Magnússon written by [his amanuensis] Jón Ólafsson of Grunnavík, in 1758–59, to which ‘some few additions’ were made until 1779.<sup>9</sup>

Indeed, a trail was thus blazed for an important literary genre enjoyed by Icelanders of different social classes in the 18th, 19th, and 20th centuries. Biography became one of the most popular literary forms, which provided a setting for “þjóðlegur fróðleikur” (the local tale tradition) in the 19th century – as Sigurður Gylfi Magnússon has explained in detail in his new book *Autobiographical Traditions in Egodocuments* published by Bloomsbury 2023, as well as in an older study *Fortíðardraumar* (Dreams of Things Past) published in Icelandic 2004.<sup>10</sup> Stories of interesting people, or of those who had experienced something unusual during their lives, enjoyed vast popularity among the bibliophile peasantry of Iceland; and that interest persists into the present day. Genealogy has always been a feature of the phenomenon.<sup>11</sup>

Icelanders have been keenly interested in genealogy ever since the island was first settled in the Middle Ages. In the beginning, the role of genealogy was first and foremost a practical one: genealogy was used to ensure that certain families maintained possession of particular pieces of land. This was probably the main underlying reason for the writing of *Landnáma-bók* (the Book of Settlements) and similar late-medieval manuscripts. Over time families became the fundamental units in Icelandic social structure and family dynasties reached their peak in the 13th century. This genealogical interest has lived on among Icelanders, even though the original purpose of genealogical knowledge has changed over time.<sup>12</sup>

The pre-history of egodocuments in Iceland, which lasted until the end of the 18th century, is consistent with trends and developments in other countries. We are of the view that from that point Icelandic literary culture diverges to some extent from that of Europe. This is especially true with respect to participation by the Icelandic peasantry: they may be said to have grasped the new thinking with both hands and related it to their own sphere of experience and knowledge, from the beginning of the 19th century.

The 19th century was, for the reasons adduced above, a period of personal expression in a variety of ways. Paper, for instance, became readily available, and writing implements too were far more easily obtained.<sup>13</sup>

Paper had, however, started to reach Iceland in the 16th century, after which the number of manuscripts written immediately rose. In the 19th century most Icelanders could read, though fewer (particularly women) also learned to write. Increasing numbers of people became direct participants in written culture. The preservation of manuscripts is clear evidence of this.<sup>14</sup>

The progress of the scribal culture influenced people's possibilities for expressing themselves in writing in the 19th century. Two more factors must also be borne in mind when considering this history. Firstly, the Icelandic peasantry had the advantage of familiarity with the world of saga literature – the Sagas of Icelanders, legendary sagas, and chivalric sagas. Ordinary people could easily place themselves in the context of autobiographical expression because their lives so closely resembled what they read in the sagas. While telling dramatic stories of feuds and bloodshed, the sagas also contained accounts of the lives of ordinary people, living much as they still did in the 19th and into the 20th century.<sup>15</sup> For the average person, daily life in Iceland had not changed much over the centuries, so it was quite natural for them to identify with what they read. It is probable that many individuals in the 19th and early 20th centuries found it easy to place themselves in a text – to place the self in the narrative of life. That did not require much imagination. But the existence of the model was important, and it influenced people's self-expression far into the 20th century.<sup>16</sup>

Secondly, many educated Icelanders who had the opportunity to pursue university study in Copenhagen were influenced by international literary trends such as realism and romanticism. Both these movements certainly had an impact on the Icelandic intelligentsia's image of themselves. The worldview entailed by these movements influenced individuals' self-image and was first manifested in autobiographies of intellectuals, and in due course in peasant writings. The distinction between the two groups – the peasantry and the intelligentsia – was, however, remarkably unclear, as both had sprung from the universal cultural background of the *kvöldvaka* or winter-eve gathering in Icelandic homes when the household sat together and worked at their tasks while one person read aloud.<sup>17</sup>

In the early 1900s, publication of autobiographies boomed. It is fair to say that the 20th century was the heyday of public self-expression, as we see in Bíbí's attempt to express herself in her autobiography.

The characteristics of the autobiography – that it is a work by one person, an account of the author's experience of their own life, and often a recollection of events that may have taken place decades before – make it a complex historical source. The autobiography has, however, had a major place in mainstream culture in Iceland for over the last hundred years.



Before going any further, one might ask: What is an egodocument? It is important to note that we make no distinction between “life writing” and “egodocuments”; traditionally the former is marked by its publication process, by a focus on categories like biographies; in a way, a wider concept covering a diverse quality of written material, which contains personal expressions in any shape or form; published or unpublished. Egodocuments as sources are usually more confined to published autobiographies, semi-autobiographies, conversational books, diaries, collections of letters and auto-fictions. In this study we argue that egodocuments cover all these sources where the individual tries to express their own ideas as clearly as they can.<sup>18</sup>

It needs to be kept in mind that in the past two decades or so some change has taken place in how egodocuments have been used, mainly because authors of egodocuments have recognized that the boundaries between truth and fiction are generally unclear in their lives, and for that reason they have started to work with those indistinct boundaries of the narrative in their writing. A considerable part of the scholarly world has followed their example.<sup>19</sup>

In a well-known Icelandic autobiography, Jóhannes Birkiland wrote about “why he became a failure.” Jóhannes’ autobiography is highly unconventional, and it is difficult to place it in the autobiographical flora, principally because the narrative is so clearly marked by the author’s mental condition. Yet that very quality makes this one of the most impressive books of justification ever published in Iceland.<sup>20</sup> Jóhannes sums up his place in the world as follows: “My entire life has truly been a terrible *suicide* from beginning to end!”<sup>21</sup> We take him as an example of a person who clearly experienced mental health issues for much of his life; and, because his narrative was “unreliable,” historians were reluctant to make any real use of its content. Jóhannes’ story, however, is of such a nature that it opens up to readers a view of a world that would otherwise be veiled in mist for most. The value of the work lies precisely in its unique perspective.

Another example of a story of a person on the margins of society is, of course, the autobiography of Bíbí in Berlín. This book will demonstrate how use can be made of sources like those that Bíbí created throughout her life, to draw out important characters of 20th-century society in Iceland. While Bíbí’s manuscript is certainly unconventional, and marginal among books published in Iceland, it fits in well with the genre to which egodocuments belong – the work is in harmony with tradition as it was manifested in Iceland in the 20th century. The structure of the work is conventional: the author commences with her childhood and teenage years, then gradually moves on into the adult years, and addresses various aspects of her life in considerable detail. This is all in accord with the conventions, but at

the same time Bíbí is in sharp contrast to mainstream autobiographies in Iceland and elsewhere.

*Expressions and the Use of Language*

Bíbí's autobiography is a complex work. It is safe to say that Bíbí sometimes prepares her text well, foreshadowing in various ways what lies ahead, and makes extensive use of simile, which makes her text particularly unusual and interesting, as will be explored below. The text of the manuscript is one thing; the material and tangible reality of it is quite another and absolutely captivating. The manuscript itself has a "three-dimensional" quality which lends it a remarkable character, due to Bíbí tracing repeatedly over each letter as if to ensure that the text will not fade. But it is the text itself that attracts the greatest attention. In order to give the reader a sense of Bíbí's style and way of writing, let us take a few examples from her story:

- Though I never scalded myself in hot water and so never got any scars from that, I have got invisible scars, and they are the work of people's malice.<sup>22</sup>
- Anna was a sunny Sunday, while Magga was like a northerly storm.<sup>23</sup>
- Begga wasn't Anna's friend, any more than a mouse is a friend of a cat. She just hung onto Anna while she could, like a lamprey attaches itself to a whale.<sup>24</sup>
- As mentioned above, Magga of Brekka was around and about and had difficulty stopping. She was like a sailing boat with a broken rudder, or a car without brakes, and she's been in a collision once, and collisions are no joke. Poor Magga got a bump, and the bump was on her stomach, and out of that bump came Beiji.<sup>25</sup>
- That's what happens when women have children by cheating on their husbands, at least in some cases. I mean that the children suffer, and people should give thought to that. When people make a mistake like that, they should place the blame where it belongs, not cover up for the culprit, let alone name children who have been conceived in adultery after a deceased husband, that's simply hypocrisy.<sup>26</sup>

As witnessed in these examples, Bíbí had strong views on moral issues. She felt that things should be done correctly, and she disliked any secret goings-on. But a particularly interesting aspect of these examples is the humor with which she recounts these serious matters – she was always ready to laugh.

Bíbí often gave the most interesting descriptions of individuals, which she embellished with a range of similes that are almost priceless. But Bíbí

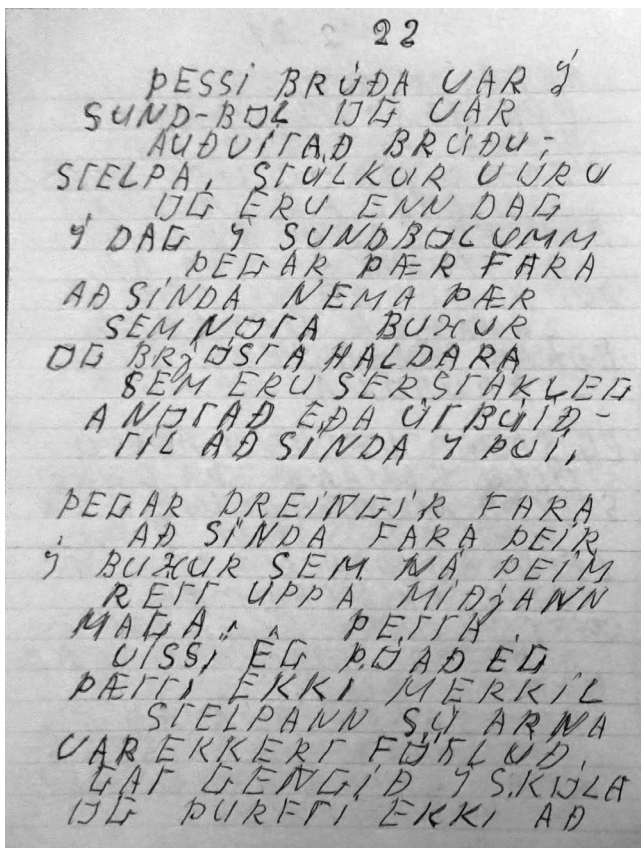


Figure 2.1 A page of the manuscript of Bibí’s autobiography

Source: Photo: Sólveig Ólafsdóttir.

Notes: As this photograph shows, the manuscript left by Bibí is highly unusual. In places, for instance, she traced repeatedly over the letters she had written, as if determined that her narrative should not be forgotten. It is hard to describe the feeling of touching the lettering in the books, which in places is “embossed” by having been traced over and over again, and is reminiscent of braille.

was also a drama queen, penning acerbic accounts that served to explain her position in the community:

- Never tell guests what is wrong with your child, if they have to be taken to the doctor, and not least if it’s something major.<sup>27</sup>
- I don’t know what would have happened if I hadn’t been cheerful by disposition. Although I had these difficulties, that I expected few people to know about, it never occurred to me to take my own life or top

myself, as it's called. Although I had little schooling I knew that you mustn't top yourself, though some people do anyway. I'm not as stupid as people think.<sup>28</sup>

- I often felt that I didn't love my parents at all, although that's a nasty thing to say. What else could be expected, with the cold treatment I so often received?<sup>29</sup>
- Of course, I started to cry about it, but do you think my mother comforted me, oh, no, she just told me to start knitting, that was supposed to comfort me. Don't you think she would have started howling if her prince had got a hole in his head, I should think so. Yes, that's the way it was.<sup>30</sup>
- A horrible storm struck in the evening, a real depression, but it wasn't from the Met Office but from my old Dad, what a storm that was. The old man said I ought to be spanked, but I didn't deserve it at all. Yes, I got to shed plenty of tears that evening.<sup>31</sup>

Throughout the manuscript BÍbí sometimes addresses the reader directly, or even certain groups of people, such as parents in general, and imparts words of wisdom. As a rule, she does so after having recounted some unpleasant experiences in her life. She does not spare her parents, as witnesses the above examples, and judges them harshly. Her father may perhaps be said to emerge worse than her mother, but the difference was not much. Her relationship with her brother Steini was sometimes rough, to say the least, and many of his friends were also depicted in very negative terms:

- I didn't care when the boy started squealing, but the thunderstorm that followed was no fun, that was from my old man. He absolutely had to take offense on behalf of the saint – it was as if that boy, who was probably 2 or 3 years old, was as eminent as the Pope in Rome.<sup>32</sup>
- The boy was in the habit of taking my underpants and hiding them under the parents' bed, then started calling out to me, teasing and mischievous, scolding me for laziness. He could talk! For sometimes he was so bone idle himself that he didn't move, any more than a worn-out old nag. He couldn't go accusing others of idleness.<sup>33</sup>
- Beiji attempted to have intercourse with me. Yes, he intended to do it, but I forbade him and defended myself from him as best I could.<sup>34</sup>
- It may be wicked to say so, but I found the three of them, the parents and the boy, often like snarling beasts.<sup>35</sup>
- Then I was confined behind the head of my bed, by the coal scuttle, while Dad dandled the boy in the guests' faces. You could say it was as if I had had 2 dolls, one old and ugly and the other straight out of the shop, and pretty. It's as if I had hidden the ugly doll and showed off the

pretty one. Do you understand what I mean? I was the ugly doll. Steini was the pretty one.<sup>36</sup>

- ... but I want to say here frankly, that I would rather have looked after a hundred chicks than the boy.<sup>37</sup>

Bíbí did not hesitate to tell it as it was when she was dealing with her parents or anyone who got in her way. They receive their own share of merciless criticism:

- As soon as I, or we, went in there and I saw him, I went wild and scorned him. It probably happened when I was to be undressed, but never mind. The old man examined me from the top, but not all the way to the toe. After that the stupid old man gave his verdict. I was supposed to be feeble in both ways, that is to say, both body and mind, but he was lying.<sup>38</sup>
- Once I heard my mother talking to a neighbor woman, saying that she would wish that I might go to heaven before her. I heard her say that in the adjacent field and was very surprised – I was 24 years old. Now as I write this, I am 58, and I am pleased in some ways that my mother didn't get her wish, for another role has been allotted to me, that's for sure. It's a rotten lie that I was difficult. From the very first I was in the habit of playing with my toys ... I'm not a mishmash like Steini was – who permitted himself to tell various untruths. I thought and considered more than him, and I wanted to get to know a person first before I said anything critical about them.<sup>39</sup>
- People like that shouldn't marry, they should just stay on the shelf and live alone, and they shouldn't have children either, at least not disabled children [referring to her parents].<sup>40</sup>

Then, at the age of 30, Bíbí lost her mother, and conflict began about where she could go. Her maternal aunts wanted to send her to a relatively newly founded institution for people with mental disabilities, the Kópa-vogur Institution. Bíbí refused to go:

- At midday, or whether it was earlier that she departed this earthly life, I don't remember, but I remember that Ebba Jóns was brought in to help out, and when it was all over Ebba told me that my mother was with God. I was so surprised that she should say that – or not really surprised, I suppose people had lied to her that I was some kind of idiot who only understood that kind of talk, the kind of talk Ebba used, or something like that.<sup>41</sup>

- I said I would never go there, and I've stuck to it, it was no boarding school, it was an imbecile asylum that Jana and Guðmundur Þórður were trying to lure me into. He can go to hell, and Jana after him – no, she'd probably go to one Adventist service first. ... And I also want to say that I've never intended to work with idiots, whether Jana reads this or not, I'll say it, it's too bad if she can't get hold of Guðmundur Þórðarson to tell him the news – that is, if she should read it.<sup>42</sup>
- I was no idiot, and I didn't belong in any institution for idiots.<sup>43</sup>

In the autobiography Bíbí makes reference to some person or other possibly reading the text, as if she is quite sure that it will be published. These references are an indication of her determination that her writings should be made public.

Bíbí had a very decided self-image; she knew what she wanted, and stuck to her guns. It hurt her feelings when she was patronized, as witnessed in



*Figure 2.2* Bíbí with her dolls

*Source:* Photograph from Kristjana Heiðberg Guðmundsdóttir (deceased), loaned by her son Ásgeir Valur Snorrason.

*Notes:* Bíbí collected dolls, and ultimately donated her collection of over 100 dolls to the National Museum of Iceland. The photograph shows her with some of the collection. The dolls brought Bíbí great joy and satisfaction, though initially she was ridiculed and scolded for “playing” with dolls as an adult.

the above quotation when she was informed that the mother was “with God.” And she was resentful when she was belittled, especially by her mother:

- I can say, and shall say, that I had been made so scatterbrained that one spring when the dung was being piled up, I did it the wrong way round. The next time a guest came visiting, my mother started telling the guest about it, blaming it on my handicap. That was just nonsense, it was because people were so horrible to me. A pauper in the old days was hardly worse off than me, or the slaves in ancient times. Yet there could be patches of sunshine, though they were fewer than the thunderstorms – the scolding and ingratitude.<sup>44</sup>
- In a sense I was like a broken machine that had to be treated carefully if the people had thought about it. It happened more than once that people acted that way and showed me both harshness, I won’t say cruelty and a lack of compassion.<sup>45</sup>
- Periods or monthlies or whatever you may call it, I got it when I was 14 years old and was entirely free of it when I turned 50, but it was rather a difficult time while I was living at home – that was something. It was no problem during the summer, then you could go outside and do it there. But it was a horrible nuisance – those who have it, or need the monthlies, such as younger people, know how revolting it is to have it in your clothes – but it’s only women who have monthlies. Never mind that. If I needed to urinate, I needed to get rid of it, the boy would prevent me from getting to the pail – there was a pail at home for doing one’s business. I sometimes got into a rage about it, shoved the boy out of the way, and said I had to do my business.<sup>46</sup>
- After a certain time, that is after her confirmation, Alda stopped coming to visit me, I was very unhappy about it, but there it was. Then I felt I no longer had anyone to talk to, I felt I was entirely isolated.<sup>47</sup>

Then the time came when BÍBÍ went to live at the retirement home in Blönduós, which appears to have been some sort of temporary arrangement. Yet she would remain there for over 17 years. When she left her childhood home, Berlín, the cottage where she had lived all her life, she looked back and bade farewell to the place where she had grown up, but not with any great sense of loss:

- The only animal I said goodbye to was the poor kitty, and I didn’t feel able to do so until I realized I must, I never saw that kitty again. That kitty had been my friend, though I didn’t always understand her, but that’s another matter.<sup>48</sup>
- I wasn’t comfortable there [at *Hælið*] and I felt like a caged bird.<sup>49</sup>

As witnessed in these quotations from Bíbí's manuscript, the content is diverse. Bíbí addresses her readers and gives them advice. She berates people when she deems it necessary and gives them a lecture! Her varied style is striking, and her pointed metaphors often make the reader laugh. Irony is ever-present in her descriptions of people and issues, and Bíbí had opinions on many issues and did not hesitate to present them in her text. On the other hand, she is a complainer, who strongly expresses her opinion of people's behavior toward her. Thus her family is often abused, especially the "little prince," her brother Steini, and also her father, and even her mother. But, as mentioned above, Bíbí had a strong sense of identity, and was generally quite certain of her virtues: "I don't know what would have become of me, if I hadn't been cheerful by disposition. I wasn't allowed to smile, let alone laugh, have you ever heard such nonsense?"<sup>50</sup>

The story demonstrates Bíbí's keen sense of humor about herself, and the way she sometimes makes fun of her own identity. On the other hand, she takes a clear stand regarding her fate and speaks out in strong terms.

There is no doubt that Bíbí noticed what happened around her; she listened, though most people apparently did not expect her to grasp what was happening. On the field trip we, the authors of the book, made to Blönduós, the town where the retirement home was located, it transpired at a public meeting we held that everyone had known Bíbí and seen her around, but as one woman remarked, "we didn't talk to her much." In a sense Bíbí may be said to have been isolated, not only in her childhood home as she recounts in the quotations above, but also in the town of Blönduós, where she lived for all the latter part of her life. She listened and heard what people were saying, but there were few who saw any reason to address her. That is undeniably a sad lot in life.

It is interesting to consider how Bíbí discusses both her illness and her body. She was very unhappy with the doctors who had diagnosed her in her early years, abusing them and judging them as incompetent. She gives several of them a piece of her mind, but after she moved to the retirement home in Blönduós she had respect and admiration for the medical directors. Her accounts of menstruation and some of her physical traits assuredly give an interesting insight into Bíbí's way of thinking and how she compared herself to the community around her.

Bíbí had striking preferences in the clothing she wore. She also had strong views about the food she was supposed to eat, and she did not hesitate to express her opinions about people's conduct. This all throws light on Bíbí's world and uncovers many interesting aspects, which will be discussed further in the book.

The first part of the manuscript is a continuous narrative of her vulnerable position in society, generally experiencing exclusion from an early age. She gradually came to understand what her situation was and sought



to resist it through an acute analysis of her own life. That is, in fact, the story of all the historical sources she built up and left behind at her death in 1999.

### **The Doll Collection**

From childhood Bíbí had a great interest in dolls, and that interest lasted all her life. As a grown woman she collected dolls, and ultimately presented her collection of 134 dolls – possibly more – to the National Museum of Iceland.<sup>51</sup> The matter of how the doll collection reached the museum is something of a mystery. It is certainly highly unusual that an unknown woman with disabilities should be able to place her doll collection in Iceland's biggest and most prestigious museum. Two stories have been told: Bíbí's friend, Anna, with whom she was in close contact in her later years, and Anna's daughters, filled their car with the dolls and drove with them to Reykjavík. This is maintained by Anna's living daughters.<sup>52</sup>

The alternative story is that the late Hallgerður Gísladóttir, a curator at the National Museum, was traveling around the country on official business, meeting people who had some direct or indirect connection to the museum. She was also on the lookout for objects for the museum collection. She is said to have been introduced to Bíbí in Blönduós, and the two women became friends. When Bíbí became aware that she would have to return to the retirement home, and could not take her doll collection with her, she is said to have asked Hallgerður to visit her and offered her the doll collection. Hallgerður is said to have accepted and transported the collection to Reykjavík for Bíbí and placed it in the National Museum collection.

Both versions of the story are vouched for by informants, but one thing is for sure: the doll collection is now in the museum's keeping.<sup>53</sup> It is entirely possible that both stories may be true: the collection may have been transported in two parts – as it is an extensive collection.

Bíbí clearly intended to get her doll collection into the right hands: she had packed the dolls up, all in their finest clothes, and attached to each a label providing necessary information about them. This stated who had given Bíbí the doll or whether she had bought it herself, the doll's name, and other salient facts about them. The dolls had been packed up with great care.

Little or nothing has been done with the doll collection since it came to the National Museum. It had lain uncatalogued in the museum's repository until our project began. A few items from the collection have been placed in the Skagafjörður Heritage Museum at Glaumbær, near Bíbí's childhood home. But it is unclear how those dolls came to be in the museum.

In connection with our research project an MA student of museum studies, Guðlaug Dröfn Gunnarsdóttir, has researched the doll collection; she defended her thesis on the subject in the spring of 2023. She has explored the collection in detail and demonstrated that for Bíbí the dolls were like her family; she thought of them as her children. They had a supportive role for her, enabling her to spend endless hours with them, thus having something to do in her solitary life.<sup>54</sup>

In her story Bíbí often makes light of her doll collection, probably because she was so often shamed for playing with dolls, and she regularly met with scorn for her hobby. Bíbí explains her interest in dolls as follows:

I was a sincere admirer of dolls as soon as I grew beyond my infant years, which I think lasted 4 years longer than normal. That was natural enough, because I didn't start walking around until I was 6, after my illness as a baby. I was probably about 8 years old when I first started enjoying dolls, so it was natural for me to take longer – or things were delayed in my case compared to others. It didn't matter if I gave it up sometimes, it always returned. If I didn't have a doll at hand, I felt something was missing, but not many people understood it. Mothers who have lost their children would understand it better, there aren't many who understand such people as me, and people like me.<sup>55</sup>

Bíbí explains her interest in dolls in an interesting manner. She identifies her playing with dolls with the conventional perception in developmental psychology of the stages of children's development, whereby normal child development is seen as one step following another, on the way to adulthood. This psychological interpretation has been criticized, not least within disability theory and by people with disabilities themselves, with reference to the fact that such an interpretation always references what is "normal" at a certain age, and children with disabilities are assessed by comparison with the "normal curve." Such norms have led to people with disabilities and others who do not conform with the conventional steps of developmental psychology, being excluded from participation in society: the old residential institutions are a clear example of this.<sup>56</sup>

It is interesting to observe that such views appear to color Bíbí's narrative, leading her to maintain that her interest in dolls lasted longer than usual because she was, in her own view, slow to develop. In addition, she explains her love for her dolls as an "outlet for motherly love." She expresses this as follows: "Can you help it if you take delight in something than you are capable of managing? There was probably some motherly love in me, since it was like that, and increased over time."<sup>57</sup>

Bíbí may thus be said to have adopted to some extent the theories of the time about disability and people with disabilities and applied them to herself.

Bíbí points out that her interest in dolls grew out of her isolation at home. She was not allowed to do anything. She was very unhappy when people criticized her interest in dolls. “It’s horribly spiteful to be criticizing people for it, you might as well forbid a cat to catch mice – that probably wouldn’t work, I don’t think so.”<sup>58</sup> Bíbí continues to explain her reasons: “I must have been over 15 when they refused to allow me to go to the Christmas party with the kids, they said I was too old to go. Of course, it was a rotten lie, I’m sure disabled people must have been allowed to go, at that age. ... And after that I was never allowed to go to any kind of social gathering, I was absolutely isolated, except when we went south to Brekka, fun as that was – or far from it.”<sup>59</sup> Bíbí then asks what she could have been expected to do to pass the time, adding: “Maybe it’s nasty of me to say that I often felt like a prisoner in a cage in my own home, or like a slave, for I was rarely asked to do something, but ordered to do it, and with no thanks afterwards.”<sup>60</sup>

Bíbí’s relatives and friends knew that she was interested in dolls, and many of them sent her dolls as gifts when she was living in the retirement home. Then Bíbí started to collect them purposefully. “After I first came to H.A.H. [*Hælið* in Blönduós], that is at the start, I didn’t get any pocket money, it must have been 5 or 6 years that I never received a *króna* in pocket money. But after Imba started there, she arranged for me to get pocket money. It wasn’t much at first, but when I started getting more Imba decided it should be paid into the bank, she said to me that it was better for me to have something in the bank, so far as I remember, and I would give her the money I didn’t need to use.”<sup>61</sup> As Bíbí acquired more money, she started to go to the local bookshop and buy books and dolls for her collection.

It is quite clear that Bíbí was sometimes embarrassed about her doll collection and concealed it. It may be inferred from the following words that in some sense she was ashamed of her hobby:

I want to point out that I don’t play with them, although some people claim that I do, that’s just imagination and nonsense. For me the dolls are like any other collection. Some people collect stamps and some collect rocks, and some have a collection of books, and it never occurs to anyone to say, neither sooner nor later, that they are playing with their collection. I may have mentioned this before, but that’s not important. Maybe people talk like that because they think I’m some kind of a fool, but I’m not. Those people are fools themselves.<sup>62</sup>

After Bíbí first moved into the home in Blönduós, she recalls being belittled when she was “pottering with the dolls” as she puts it. She mentions one woman in the home: “Then the old woman said: ‘You’re strange, doing that, you’re not like other girls, they sew and knit and crochet.’”<sup>63</sup>

As mentioned above, Bíbí found life at the home tedious, and her dolls gave her something to do. She sewed clothes for them, acquiring fabrics here and there. The dolls’ clothes bear witness to Bíbí’s good taste, creativity and meticulousness, and they reflect the tastes and fashions of the time when they were made. Bíbí also recalls visitors to the home making fun of her and her dolls: she responds as follows:

And it may as well be said here that it was a solitary person who owned the dolls and enjoyed them, and since the staff, and especially the bosses, didn’t forbid her having them, visitors to the home had no right to go interfering about the dolls.<sup>64</sup>

Here again, Bíbí’s words may be seen as indicating that for her the dolls took the place of the family she would have wanted to have. Bíbí’s contemporaries in Blönduós recounted that she often held coffee parties for the dolls, arranging the largest around the kitchen table, baking *lummur* (small pancakes) and holding parties with them. Bíbí’s relatives in Hofsós recalled her bringing several dolls with her when she visited; the children of the family were allowed to see the dolls, but absolutely not to touch them.<sup>65</sup> Bíbí appears to have treated her dolls as if they were living beings, her children whom nobody must treat cruelly. She named the dolls after people she liked.

As previously stated, Bíbí was the butt of considerable abuse after she moved out of the retirement home, especially from the children in Blönduós. She was often subjected to teasing and mischief by children. Bíbí, however, did not blame only the youngsters for the tricks; she attributed the behavior to the children being badly brought up and not properly informed, as witness her words of advice above.

The doll collection is assuredly evidence of Bíbí’s zest for life, and her efforts to create things and enjoy her life. In that way she found a purpose in life and created a world in which she was a full participant, and had complete control over. The state of the collection also indicates how determine Bíbí was keep her material belongings in good shape. She did not hesitate to continue collecting dolls even though people around her repeatedly tried to convince her to get rid of them. In this sense it may be argued that the doll collection is a strong testimony of Bíbí’s strong will to manage her life in the way that worked best for her. She saw it as an opportunity to enjoy life – on her own terms.

## The Garden

“Fagrihvammur” [Fair Dell]: That is what I call the garden, it becomes ever dearer to me as time passes, and I am both hurt and angry if anything is done to spoil it for me, it’s become so very beautiful, in the circumstances.”<sup>66</sup> This is how Bíbí describes her garden, which she saw as her greatest achievement in life. The garden brought her great joy, and she was proud of it. The garden was located just outside Blönduós, about four kilometers from the retirement home where she was living when she started to make the garden from a gravel pit owned by the town – a sort of no man’s land. Bíbí probably started to make the garden in 1972. She describes the beginning as follows:

I was once walking out this way, and I walked farther than I usually did. When I’d gone quite a long way I saw a big, strange pit, that looked like a pit where road-building materials had been quarried, which it probably was. That pit was full of all sorts of trash, shoes, bits of wood, and this and that. I liked it at once.<sup>67</sup>

At the end of her autobiography Bíbí again mentions the start of her gardening. “To return to that chance event, so to speak, I was probably meant to remain in Blönduós, who knows? And I was probably meant to transform a filthy pit into a beauty spot.”<sup>68</sup> From the time that the snows thawed in spring, and until the autumn, for 30 years Bíbí went to her garden every day – first from the retirement home, then from Aðalgata 7 and finally from Bíbí’s House.

Through her gardening Bíbí found an outlet for her interest in nature, creativity, and love of the land. She was a true child of nature, and in her childhood home she had enjoyed rewarding relationships with the animals on the farm. She had sheep of her own, of which she was very fond, and the cats were dear to her. She enjoyed being outdoors and wandered around the surrounding area as much as she could, particularly when her father was not at home.

Clearly, through her gardening activity Bíbí initially found a way to be out of the retirement home, outside in nature, and have something to do in her often-monotonous life. The garden became her happy place, her refuge in all weathers. It is just another testimony to her strong will to take control of her own life, to use her imagination to build up something positive, something important that she could work on, day in and day out. The garden almost became a place in her own world, where she was both the ruler and the master of ceremonies.

She often took some of her dolls with her to the garden, as if she wanted them to enjoy with her what the garden had to offer. She either



*Figure 2.3* Bíbí in her garden

*Source:* Photo: Ari Sigvaldason.

*Notes:* Bíbí in Fagrihvammur (Fair Dell). She took diligent care of her garden, which she had created from scratch in a former quarry pit and eyesore. It was about five kilometers from *Hælið*. Bíbí walked there carrying water, plants, gravel, soil, clay and gardening implements. The garden was Bíbí's pride and joy, providing her with boundless delight for nearly three decades.

bought the plants for her garden or cultivated them herself. Bíbí recounts that friends in Blönduós and relatives in Reykjavík started to send her seeds and plants when the garden began to take shape. She grew flowers, plants, and potatoes in raised beds, which she diligently constructed herself.

In the early years Bíbí took care of her garden alone, without any help from others. In the autobiography she recounts carrying plants, gravel, soil, clay and tools to the garden. Later, she was assisted by friends and by municipal employees; she makes special reference to Knútur Berndsen. He helped her in many ways; for instance, he provided a small hut where she could take shelter and enjoy her coffee and picnic. She called it her *garðhús* (garden house). Knútur also erected a fence around the garden with the assistance of some municipal employees; this was necessary, according to Bíbí, not least because the local children persecuted her there, and often vandalized the garden. She remarks:

The next day when I went out there, most of the flowers had been uprooted, and some of the things I had made had been moved. I flew into a rage over such a brutal outrage against the flowers. The day after so much had been vandalized, there was more vandalism, after I had put right the damage from the day before. I had to put that later vandalism right too, and there was still vandalism on the third day, but less. Nonetheless, I was furious, and I swore to get back at the people who had done it.<sup>69</sup>

Fencing the garden in proved not to be enough; people continued to enter it with bad intentions. Bíbí saw the vegetation and flowers as living beings, and was severely distressed when vandals targeted the garden: “They can’t [get it into] their heads that flowers are living beings like them, but the flowers are stuck on their stems and can’t get away, while the boys can.”<sup>70</sup>

There is no question that this activity gradually got people’s attention and earned Bíbí a certain respect among the locals. The garden was in a sense Bíbí’s opportunity to show her contemporaries what she was capable of. The town of Blönduós finally granted Bíbí recognition for her garden in 1991, and that appreciation was of great value to her. When she looks back over what she has done at the end of her autobiography, she takes the greatest pride in her garden.

The garden has now largely disappeared; the remains of her raised beds are visible, and a few plants have survived. But after Bíbí’s death no-one saw any reason to maintain the garden in the middle of nowhere, and now it is just a shadow of its former self – its former glory.



Figure 2.4 Award for the garden

Source: Photo: Jón Sigurðsson.

Notes: In 1991 Bíbí received an award for her garden from the Blönduós Town Beautification Committee. That recognition was of huge value to her. When she looks back over her life and deeds at the end of the autobiography, she takes the greatest pride in her garden. It has now largely disappeared, though traces of raised beds are visible, and some plants have survived.

## Collection of Books and Manuscripts

### Books

From her early years Bíbí was keenly interested in books and reading, and she soon acquired books of her own. She reports owning about 30 books at the time she moved out of her childhood home, Berlín. She took them with her. After her move to Blönduós she added more, and at the end of her life she stated that she owned over 100 books. She had either bought them herself or received them as gifts from friends and relations on various occasions. Bíbí states *inter alia* that her father sent her books after she left home; according to Bíbí her parents were book lovers who encouraged her to read from an early age. Her father Kristján appears to have wanted to support his daughter's reading after they parted. In her early years Bíbí was keen to read books of all kinds, while in later life she was mainly interested in books dealing with local tale traditions (Icelandic *þjóðlegur fróðleikur*) and travel books.



Bíbí's library has been the subject of various interpretations. When our research team visited Bíbí's home district in the spring of 2022, we met her relative who lived on the farm Brekka, who was about 77 years old and Bíbí's junior, and a close friend of her brother Steini.<sup>71</sup> We visited his home in Hofsós, where we met him, his wife and their daughter, who gave us information about Bíbí. They had seen the autobiography, which had recently been published, and the husband was not greatly impressed. In the book Bíbí recounts various stories about his mother that he could hardly be expected to welcome. She asserts, for instance, that he had been wrongly fathered, and that his mother had been promiscuous. In the autobiography Bíbí recounts many humorous and even embarrassing stories about the interest that "Auntie Magga" displayed in the opposite sex.

The husband was skeptical that Bíbí had been able to read, maintaining that she had collected books mainly in order to show off and exaggerate her own importance. Eventually, she had her own phone at the retirement home, he said, and traveling booksellers had called her, managing to fool her into buying books which remained unopened – "all still in the shrink-wrap" – as he put it. We immediately asked what had happened to Bíbí's possessions after her death. He reported that he and Steini had gone and fetched her stuff, which was in storage at his mother's house, next to his own home in Hofsós. The space had, admittedly, been unheated for 15 years, so the possessions were certainly not in good condition.

We immediately asked permission to see Bíbí's things, and that was no problem. In a small room in the house were about eight large boxes full of books. Surprise, surprise! All of them had been read. The books were in poor condition due to damp and mold, but an examination revealed a number of rural romances, a considerable number of books from the local tale tradition, many books about nature and gardening, and finally books on machinery and equipment. Clearly, Bíbí had diverse interests and had acquired a large number of books: the volumes stored away in the boxes numbered about 130.

Bíbí writes that when she lived at the retirement home in Blönduós some people commented on her library: some expressed doubt that she knew how to read, and some of the elderly ladies who lived at the home in her time suggested that she ought to sell her books, as they were no use to her. The inference was that she could not read. Bíbí, on the contrary, saw her library as proof that she could read, which gained her more respect:

But I wanted my own library, the other books in the library at the home were not to my taste, that's for sure. I think people thought I had no need to own books, and there is also the other thing, that

if I hadn't any books it would be easy to claim I couldn't read. But you can't say that about people, if they own books, or at least that's my view.<sup>72</sup>

Here, we see a fine example of Bíbí's independence and her desire to act for herself. She does not hesitate to resist and ignore objections to things that were important to her.

It is obvious that Bíbí's library was important to her, and it is evident that she made good use of her books, as this is revealed in the text she wrote. Her manner of expression and her way of thinking clearly indicate that she had gained her knowledge of the language by reading books. It is also interesting that she was fond of her library; it was important to her to acquire books, and she displayed them as a signifier of her status and dignity, though their function was primarily to help her pass the time and seek self-improvement.

### *The Diary*

To revert to the research team's visit to Hofsós in 2022, when we met Bíbí's relatives, we went through the boxes which had been stored in the mother's home. In the last box we found notebooks – exercise books – which we decided to examine more closely. They turned out to be Bíbí's diaries.<sup>73</sup>



*Figure 2.5* Photograph of the diaries

*Source:* Photo: Sólveig Ólafsdóttir.

*Notes:* Bíbí's diaries, photo albums and other items were discovered by pure chance in the spring of 2022. They had been stored in a house in Hofsós that belongs to a member of Bíbí's family, which had remained unheated for more than 20 years, so the books were very damp and musty. The content of these books opened up an entirely new perspective on Bíbí's interests.

This discovery took the three of us by surprise, and we asked if we could take the exercise books back to Reykjavík with us. The husband agreed and was simply happy to be rid of that stuff, as he said. Equipped with two black plastic sacks, we packed up the diaries, which were very smelly. In that condition we brought the diaries to Reykjavík and did our best in the first few days to dry them out on a washing line. There were 50 books, of which a hasty transcription was made.

The diaries revealed that Bíbí started to keep a daily diary just before 1970, or soon after she had finished the *Annal* that will be discussed in the next section of this chapter. They do not add much to what we know about Bíbí, but it is assuredly interesting to learn that she kept a diary for over 15 years or well into the 1980s. Even though they do not add much to our knowledge about Bíbí, the diaries give us some insight into her desire to express herself. It is quite a task to stick to one's guns and go on year after year writing about daily affairs. She does not use a lot of words; most of her writings are about the weather, and very briefly what she did that day. We gain a good view into her times in her garden and what kind of effort went into keeping it nice and orderly. Her handwriting is not good, the letters are not very clear, and it is sometimes difficult to understand what she is saying.

All things considered, we can say that the diaries do not give us much insight into Bíbí's life except the fact that she kept them for all those years. Still, the diary is just one more element of Bíbí's archival expression, and as such it is outstanding evidence of her will to record her own life.

Among the papers found in Hofsós on our research trip was a book of drawings by Bíbí, a text that she had collected of poetry written by someone else, and finally a book of Christmas cards that she had collected. All of this material has given us insight into Bíbí's way of thinking.

### *The Annal – Poetry*

When we started to examine further the written documents we had received from Hofsós, we were astonished to come across, in one of the books, a sort of annal of Bíbí's first ten years at *Hælið*.<sup>74</sup> What is more, it was written as a continuous poem, which extended over 100 pages of the book. It must be acknowledged that we were taken aback; we did not know what to make of this extraordinary discovery. It is one thing to recount in writing the story of one's life and conflicts with people and issues, but to express it in verse is quite another, and the text is on a different level.

It is not easy to describe the content of the annal and judge its "quality," so to speak. Bíbí composed the poem for a friend, Björg, the wife of the first medical director who was responsible for her care at the retirement home. The couple moved away some years after Bíbí had found a

new home in Blönduós. The narrative approach is simple. Bíbí tells stories of the people who were around her, and her relations with individual residents of the home, friends, and enemies. The descriptions are full of humor, and Bíbí sometimes speaks out frankly when writing about individuals she dislikes. She expresses great admiration for her friend Björg but clearly states that she must not show her husband (the former medical director) Bíbí's writings. It is not clear why she imposed this prohibition, as she was always on good terms with him.

The annal has, in a sense, a different flavor from the autobiography. It was, of course, composed when she was still living at the retirement home, and the events were closer to her in time and fresh in her memory, so she has not yet achieved the distance she had later in life when she wrote the autobiography. Hence the annal is in a sense more powerful than the autobiography – it is rawer and more forthright.

The poetry itself is variable. Sometimes Bíbí is successful, while on other occasions she forces into verse statements that do not fit in with the form – since she is telling her story, and she often has to bend the rules of prosody, or poetic rhythm, to do so.

The simple fact of having composed a body of verse of a hundred pages is a spectacular achievement. Bíbí was no doubt proud of herself after having successfully completed her task, sent it to her friend, and received her response – although we do not know what that was. But we may easily imagine what it may have been: this is such an amazing achievement by a person such as Bíbí that her friend can only have been astonished at her having composed a work of poetry of this scale.

In her foreword to the poem Bíbí writes:

It is a long time since I first had the idea of making this annal to commemorate my ten-year stay here. I had intended to dedicate it to the best friend I have had in my life. In case she might enjoy it.

And this winter I made a start, and continued off and on, putting together various informative or entertaining things. Some of it is old, taken from exercise books in which I'd written this and that, and I based some of it on that. I hope my friend won't be bored to receive this long piece of writing from me. But there is one catch. Páll, my friend Björg's husband, must absolutely not have access to this annal, but Pella, your daughter, may look at it if she has time. In order that Mr. Páll, former physician in the past in the Blönduós district, should not be too disappointed not to read the annal, I shall send my former overlord a picture of Víði(mýri) Church in Skagafjörður.

1958 to 1968.

10-year annal.<sup>75</sup>

Bíbí starts her poem with the following words:<sup>76</sup>

It is nearly ten years now  
Since I took my first steps here  
Sometimes fun and sometimes not for me.

Should I blame my Auntie Jana for it  
She wanted to send me to this place  
And leave me here for a while

Then shove me into an institution for idiots.  
But it's quite another thing  
That tedium and sadness oppressed my soul  
My temper was often resentful  
Oppressed by Miss Sigurbjörg.<sup>77</sup>

Finally, she speaks warmly of her friend:

Oh, yes it happened  
That Björg was later my best friend  
She is the kindest and best of people  
And her husband is Mr. Páll.<sup>78</sup>

And her story continues, as she enumerates everybody she has known and gives her assessment of them, telling their stories in various ways. The text is powerful, and in places extraordinarily perceptive and clear. Bíbí makes many complaints about her fate, yet at the same time it is obvious that she had meaningful interaction with many people at the retirement home, often marked by humor and teasing.

The annal comprises no fewer than 436 stanzas, which vary in length from three to eight lines. In many cases she inserts a heading for the following stanzas, thus breaking up the long poem into sections. Much is philosophical in nature, while other verses concern her immediate community, and she often alludes to her story and her fate. She did not hesitate to give her aunts a piece of her mind – for she held them largely responsible for what had happened to her:

You have hurt me, that will not be forgotten  
and my faith in you will not be restored  
I'll say no more, that's something else.  
I have friends in Björg and old Páll.

Poverty is no burden on you  
Not for the time being  
But to leave me in a strange place.  
I have never forgiven Jana for it.

To start with here I had many a sorrow  
And my temper was terribly resentful  
One person was not afraid of my outbursts  
she was as a mother to me, Björg, the darling dove.<sup>79</sup>

The annal is a different kind of evidence of Bíbí's life from that seen in the autobiography, but at the same time it provides astonishing insight into Bíbí's ability to take control and have an impact upon how she worked through her issues, and how her contemporaries, and later researchers, saw her on her own terms. There is a striking potency in her expression, a certain refusal of compromise, which is rarely seen in old narratives. In that sense Bíbí makes her entrance as a fully-formed poet who has much to say and does not hesitate to put forward her thoughts and mindset. This late addition to the archive of Bíbí in Berlín is one of the most extraordinary features of any life we have encountered in our research history.

With the written documents we had received from Hofsós there were two copies of this *Annal*, almost identical. One is a little more organized than the other, and both were over one hundred pages.

### *Illustrations*

We have made an attempt to locate as much photographic material as possible from Bíbí's life. Some of it she kept herself, while we have found other photos in archives and in the keeping of relatives. We plan to use these illustrations to demonstrate many of the activities Bíbí undertook and study her images from one time to another.

The majority of the images used originate from photographic collections owned by two of Bíbí's cousins and their respective families, namely Áslaug Gunnsteinsdóttir and Kristjana Heiðberg Guðmundsdóttir. They were Bíbí's first cousins, daughters of her mother's sisters. Áslaug and Kristjana are now deceased, but their sons were contacted and assisted in providing access to these photographs. Notably, Áslaug and her husband, Ólafur Jens Pétursson, had entrusted their collection to the District Archives of Kópavogur, within which were discovered some images featuring Bíbí and her family that have been incorporated into this book. Gunnsteinn Ólafsson, Áslaug's son, offered valuable insights during a guided tour of the gallery and shared significant information. Similarly, Kristjana's son, Ásgeir Valur Snorrason, generously contributed numerous photographs featuring Bíbí and her family. These images offer valuable perspectives into the lives of Bíbí and her family, especially during her formative years and adolescence. They encompass family portraits featuring Bíbí, her parents, and her brother. Additionally, there are photographs depicting moments such as the death of

Bíbí's mother, including an image of her casket standing outside the house at Berlín. Furthermore, there are photographs from Bíbí's seventieth birthday celebration, featuring various family members and friends of Bíbí. Moreover, photographs from Bíbí's funeral and burial have been included, providing insights into her life and circumstances, encapsulating both sad and joyful occasions, such as birthdays and visits from relatives.

Within the District Archives of Blönduós, a selection of images featuring Bíbí during her time at *Hælið* was discovered, including a photograph featuring Bíbí wearing Icelandic national costume alongside a group of people from *Hælið*, all of whom are identified by name. Another image of Bíbí, presumably taken around Christmas before 1970, was uncovered. Additionally, a chance encounter led to the discovery of a photograph of Bíbí in her garden. A passing photographer, circa 1980, had sought Bíbí's consent to take her portrait.

We made an attempt to locate more illustrations from the life of Bíbí but without success. We received information about the possibility of a video film that one of the staff members from *Hælið* had taken but we were unable to find it. We are sure that more pictorial material is to be found in boxes in basements among Bíbí's friends and relatives, but no more can be done at this time.<sup>80</sup>

### Counter-archive

When we look back and consider Bíbí's achievements, and all that she created and made public in one way or another, the result is astonishing. She creates, or simply lives, her life and succeeds in leaving behind a trail that provides us with the opportunity to examine her ideas about herself and others.

It is tempting to try to link the concept of *counter-archive*, and *embodiment* in a textual sense, or incarnation, with Bíbí's deeds. The author – Bíbí herself – plays with the presentation of her own personality through her text: a certain form of discourse that she uses to give herself a voice – an agency.<sup>81</sup> At the same time she embodies herself in the reader's and listener's mind, manifested in direct speech, heteroglossia, and personification, in her text.

This is a kind of “embodied connectedness,” whereby the thing takes form as an “embodied” phenomenon by the signifiers in her text merging with the recipient. This entails that Bíbí applies the idea of *embodiment* in her collecting of various objects – text, dolls, books, plants, poetry, diary – and puts it forward in opposition to the idea of the “feeble-minded,” the

label the “progressive medical sciences” had invented and applied to people like BÍbí. She contrives to make her materials into an organized *counter-archive*, and the explanatory model is her “emotional community,” which will be discussed further in this book. Counter-archives are usually seen as political, resistant, and community-based. They are embodied to disrupt conventional national narratives and write differences into public accounts. And they are formed to counter the hegemony of traditional archival institutions that have normally neglected marginalized groups of people.<sup>82</sup>

*Embodiment* is, of course, a difficult concept to deal with, as it has so many possible meanings.<sup>83</sup> In the autobiography it applies to cases where the voice is embodied – whether in a literal embodiment, e.g., in the performance of a work, in which the performer gives the work a voice as BÍbí does in her writings. She does this e.g. in a textual sense, where the author plays with the presentation of characters through text, a certain form of discourse, and other factors in order to give them a voice, and at the same time she succeeds in embodying them in the mind of the reader/listener. She accomplishes in doing so, for instance, most effectively in her poetry. This is what we referred earlier as “embodied connectedness,” i.e. that the thing takes form as an “embodied” phenomenon in this dialogue between the signifier and the recipient.

We are in effect working with an unusual scenario and the life experience of one individual, and we have the opportunity to show how these are “embodied” in BÍbí’s presentation in so many fields. It is this transformation that takes place from the unclear – BÍbí’s life – into an embodied thing or phenomenon relating to her, that reveals both her own attitude to life and the grand narrative of the 20th century (the progress of the medical sciences). In this way we have the opportunity to examine BÍbí’s life and her perspective as a woman with a disability and measure her against the science of her time, 20th-century society, and the people who were part of her life. All that BÍbí did may be viewed as a “counter-archive,” an attempt to counteract the idea of “normal” behavior.

With this approach we move into an area of scholarship within the humanities and social sciences that might be called “potential history.”<sup>84</sup> We use the term “potential history” as it was used by Polish scholar Ewa Domańska, who argues that when she explored the unrealized potential in the past in an attempt to show what conditions should be created in order to allow people to become accustomed to each other, and how they could coexist, even in conditions of conflict. The potential for interpretations and studies of uncomfortable subjects is almost inexhaustible, using the autobiographical focus, as we will demonstrate in this book.



**From the Autobiography – *Bibí in Berlín****A Boy is Born*

*One day, no, it's wrong to say that, one evening in August it happened that my mother became ill, not dangerously so. I was in bed, or going to bed. When my father came in, she sent him off in a hurry and quickly undressed. Then my grandmother on my father's side suddenly came and told my mother that she could have sent me, I could have gone while it was still light, but after it started to get dark I doubt I could have done it, I was no genius in the dark in those days. Well, after a certain time my father came back with the midwife. Soon after, a boy was born and cried loudly, grandma took care of the little boy while they were getting the afterbirth and doing other things like that, to take care of the birthing mother. The baby was then bathed and fed sugar water. I remember saying something like, "I don't want this noise." This happened on 26 August 1936.<sup>85</sup>*

*Once when there were guests at home, I was confined behind the head of my bed by the coal scuttle while Dad dandled the boy in the guests' faces. It was as if I had two dolls, one old and ugly and the other straight out of the shop. It is as if I had hidden the ugly doll and showed off the pretty one. Do you understand what I mean? I was the ugly doll. Steini was the pretty one.<sup>86</sup>*

*The Rhubarb Storm*

*This is an unusual title. This was not a normal storm like those caused by natural forces, it came from my father. Once, but first it must be mentioned that earlier that summer, because this was during summer, he had bought, or so I believe, rhubarb, two clumps from farms or out in the country. A place was chosen south of the sheepshed, and the rhubarb was planted there, it grew as rhubarb should, if everything is normal. Then one nice day, when the rhubarb had grown enough, I remember a woman came and asked to buy some stalks. Yes, my mother agreed, and then there was no more about it for a while. I guess Dad was home, at least in the evening, that much is certain, he said nothing the first time when she sold the stalks. But in the evening another woman came and asked my mother for rhubarb stalks, she let this woman have some stalks too. After she had left, the old man became terribly angry and blew up like a northeaster and said that she had no right to sell the stalks, the rhubarb belonged only to him, but then why didn't he say that right away? I don't understand it. And regardless of the first woman, I thought it was unnecessary to behave like that, though this second woman bought a few stalks. I thought it was nasty of him to act that way and I still think so. The woman who came later was very*

disabled and had a hard time walking, I always felt sorry for her. The other thing is, I thought my parents owned it jointly, like everything else, I mean the rhubarb and the farm in general. If I had been normal, I would have talked to him. I would simply wish that he and my mother had never met; she deserved a better man. However, why do men like that get hold of women and marry them? Probably so that they will wait upon them.<sup>87</sup>

## Notes

- 1 See an interesting dialogue about “history without documents,” which relates to regions of the globe which were categorized as colonies, where sources were “tainted” by the perspective of the overlords – the colonial powers – if, indeed, any such sources existed. See Farina Mir, “Introduction. AHR Roundtable: The Archives of Decolonization,” *American Historical Review* 120:3 (June 2015): 844–950. Each of the following contributed a paper to the Roundtable: Caroline Elkins, Todd Shepard, Jordanna Bailkin, Sarah Abrevaya Stein, Omnia El Shakry, and Reuben Neptune.
- 2 Antoinette Burton, “Introduction: Archive Fever, Archive Stories.” In A. Burton, ed., *Archive Stories: Facts, Fictions, and the Writing of History*. Durham: Duke University Press, 2005, 3.
- 3 See Rosa Braidotti, “In Spite of the Times. The Postsecular Turn in Feminism,” *Theory, Culture and Society* 25:6 (2008): 1–24.
- 4 Ewa Domańska, “Affirmative Humanities,” *History – Theory – Criticism*, 1 (2018): 17.
- 5 *Ibid.*, 18.
- 6 *Ibid.*, 22.
- 7 *Ibid.*, 23.
- 8 See Matthías Viðar Sæmundsson, “Bókmenntir um sjálfíð.” In H. Guðmundsson ed., *Íslensk bókmenntasaga III*. Reykjavík: Mál og menning, 1996, 112–143. [Literature of the Self].
- 9 Matthías Viðar Sæmundsson, “Bókmenntir um sjálfíð,” *Íslensk bókmenntasaga III*, 123.
- 10 Sigurður Gylfi Magnússon, *Autobiographical Traditions in Egodocuments: Icelandic Literary Practices*. London: Bloomsbury, 2023; Sigurður Gylfi Magnússon, *Fortíðardraumar. Sjálfsbókmenntir á Íslandi*. Sýnisbók íslenskrar alþýðumenningar 9. Reykjavík: Háskólaútgáfan, 2004.
- 11 Anna Heiða Baldursdóttir, Atli Þór Kristinsson, Daníel Guðmundur Daníelsson, Marín Árnadóttir, Sólveig Ólafsdóttir and Sigurður Gylfi Magnússon, *Þættir af sérkennilegu fólki. Menning fátæktar*. Sýnisbók íslenskrar alþýðumenningar 28. Reykjavík: Háskólaútgáfan, 2021. [Tales of Peculiar People: The Culture of Poverty].
- 12 Sigurður Gylfi Magnússon, *Wasteland with Words. A Social History of Iceland*. London, Reaktion books, 2010), 147–165.
- 13 For development of writing implements and ink in Iceland, see Ólafur Halldórsson’s paper: “Skrifaðar bækur.” In Frosti F. Jóhannesson ed. *Íslensk þjóðmenning VI*. Reykjavík: Þjóðsaga, 1989, 77–79. [Written Books].
- 14 Sigurður Gylfi Magnússon and Davíð Ólafsson, *Minor Knowledge and Microhistory. Manuscript Culture in the Nineteenth Century*. London: Routledge, 2017.

- 15 See Viðar Hreinsson, ed., *The Complete Sagas of Icelanders*, 5 vols. Reykjavík: Leifur Eiríksson, 1997.
- 16 Sigurður Gylfi Magnússon, “Living by the Book: Form, Text, and Life Experience in Iceland.” In M. J. Driscoll and A. Kuismin, eds., *White Field, Black Seeds: Nordic Literacy Practices in the Long Nineteenth-Century*. Helsinki: Finnish Literature Society, 2013), 53–62.
- 17 Sigurður Gylfi Magnússon, *Menntun, ást og sorg: Einsögurannsókn á íslensku sveitasamfélagi 19. og 20. aldar*. Sagnfræðirannsóknir 13. Reykjavík: Háskólaútgáfan, 1997, 113–120; Guðmundur Hálfðanarson, “Private Spaces and Private Lives: Privacy, Intimacy, and Culture in Icelandic 19<sup>th</sup>-Century Rural Homes.” In P. François, T. Syrjamaa, H. Terho, eds., *Power and Culture: New Perspectives on Spatiality in European History*. Pisa: Plus-Pisa University Press, 2008, 109–124.
- 18 See Leonieke Vermeer, “Stretching the Archives: Ego-documents and Life Writing Research in the Netherlands: State of the Art,” *Low Countries Historical Review* 135:1 (2020): 31:69.
- 19 See for example the two following articles: Giovanni Levi, “The Use of Biography.” In H. Renders and B. de Haan, eds., *Theoretical Discussions of Biography: Approaches from History Microhistory, and Life Writing*. Lewiston: The Edwin Mellen Press, 2013, 89–111; Sabina Loriga, “The Role of the Individual in History: Biographical and Historical Writing in the Nineteenth and the Twentieth Century.” In H. Renders and B. de Haan, eds., *Theoretical Discussions of Biography: Approaches from History, Microhistory, and Life Writing*. Lewiston: The Edwin Mellen Press, 2013, 113–141. Also a new book by Sigurður Gylfi Magnússon, *Autobiographical Traditions in Egodocuments*.
- 20 See further discussion of Jóhannes and his autobiography in an essay by Þorsteinn Antonsson, “Utangarðsskáldið Jóhannes Birkiland,” *Skírnir* 159 (1985): 225–258.
- 21 Jóhannes Birkiland, *Harmsaga æfi minnar. Hvers vegna ég varð auðnuleysingi*. Reykjavík: Höf., 1945–1946, 315.
- 22 Guðrún Valgerður Stefánsdóttir, *Bíbí í Berlín. Sjálfsævisaga Bjargeyjar Kristjánsdóttur*. Sýnisbók íslenskrar alþýðumeningar 29. Reykjavík: Háskólaútgáfan, 2022, 139.
- 23 Stefánsdóttir, *Bíbí í Berlín*, 61.
- 24 *Ibid.*, 229.
- 25 *Ibid.*, 193.
- 26 *Ibid.*, 194.
- 27 *Ibid.*, 130.
- 28 *Ibid.*, 204.
- 29 *Ibid.*, 83.
- 30 *Ibid.*, 127.
- 31 *Ibid.*, 135.
- 32 *Ibid.*, 158.
- 33 *Ibid.*, 204.
- 34 *Ibid.*, 206.
- 35 *Ibid.*, 133.
- 36 *Ibid.*, 135.
- 37 *Ibid.*, 144.
- 38 *Ibid.*, 129.
- 39 *Ibid.*, 208.

- 40 Ibid., 156.
- 41 Ibid., 217.
- 42 Ibid., 219.
- 43 Ibid., 235.
- 44 Ibid., 155.
- 45 Ibid., 157.
- 46 Ibid., 158.
- 47 Ibid., 189.
- 48 Ibid., 222.
- 49 Ibid., 225.
- 50 Ibid., 176.
- 51 Þjms – Bjargey Kristjánsdóttir (Bíbí): Doll collection 1991-11-1 til 1991-11-60; 1991-11-61 til 1991-11-92; 1991-11-93 til 1991-11-132.
- 52 Oral interview, Guðrún V. Stefánsdóttir with Lilja Hauksdóttir and Sesselja Hauksdóttir, 16 March 2022.
- 53 See MA thesis by Guðlaug Dröfn Gunnarsdóttir, “Bíbí í Berlín: Brúðufjölskylda – efnisheimur og túlkun.” Félagsfræði-, mannfræði og þjóðfræðideild. Félagsvísindasvið Háskóla Íslands, júní 2023.
- 54 Guðlaug Dröfn Gunnarsdóttir, “Bíbí í Berlín: Brúðufjölskylda – efnisheimur og túlkun.”
- 55 Guðrún Valgerður Stefánsdóttir, *Bíbí í Berlín*, 162.
- 56 Mark Priestley, *Disability. A Life Course Approach*. Cambridge, UK: Polity Press, 2003, 64–65.
- 57 Stefánsdóttir, *Bíbí í Berlín*, 162.
- 58 Ibid.
- 59 Ibid., 163.
- 60 Ibid.
- 61 Ibid., 315.
- 62 Ibid., 319.
- 63 Ibid., 231.
- 64 Ibid., 353.
- 65 Oral interview: Unnamed source, 27 June 2021.
- 66 Stefánsdóttir, *Bíbí í Berlín*, 303.
- 67 Ibid., 277.
- 68 Ibid., 359.
- 69 Ibid., 278.
- 70 Ibid., 322.
- 71 Research trip taken in April 2022 to north Iceland. Interview: unnamed relative. Date: 24 April 2022.
- 72 Stefánsdóttir, *Bíbí í Berlín*, 266.
- 73 Diary of Bjarney Kristjánsdóttir (Bíbí) – manuscript: private collection.
- 74 Annal of Bjarney Kristjánsdóttir (Bíbí) – manuscript: private collection.
- 75 Ibid.
- 76 It must be kept in mind that it is difficult to translate poetry, and this translation cannot do justice to her understanding of its function. The reader should bear this in mind, and remember that this is an attempt to give an idea of the extraordinary uniqueness of Bíbí’s expression throughout her life. The original text in Icelandic will be shown in the notes. All of this text comes from the following source: Annal of Bjarney Kristjánsdóttir (Bíbí) – manuscript: private collection.
- 77 Það eru liðinn bráðum 10 ár/ Síðan ég steig hér mín fyrstu spor/ ýmist fallett eða leiðinlegt hjá mér. Á ég að kenna Jönu frænku um það/ Hún vildi koma

- mér á þennan stað/ Og hafa mig þar í bili/ Og klessa mér svo niður á fávitaheimili. Það er svo aftur annað mál/ Að leiðindi og dapurleiki ásóttu mína sál/ Oft í skapi ég var þá örg/ Mig ásótti fröken Sigurbjörg.
- 78 Ó já þar fór nú svona/ Hún Björg var seinna mín besta vinkona/ Hún er mesta og besta gæðasál/ Og á firir mann hann Herra Pál.
- 79 Þú hefur sært mig, því verður ekki gleymt/ og traust til ykkar verður ei afturheimt/ Ég segi ei meira um það en það er annað mál./ Ég á að vinum Björgu og gamla Pál. Hún sligar ykkur ekki fátæktin/ ekki núna kannski fyrst um sinn/ en að skilja mig eftir á ókunnugum stað./ Ég hef aldrei fyrirgerið Jönu það.
- Hér var í fyrstu hjá mér mæða mörg/ og í skapi hræðilega örg/ að hreyta illyrðum var ein persóna ekki rög/ reyndist mér sem móðir blessuð dúfan Björg.
- 80 See list of illustrations.
- 81 Agency is here defined as one's capacity "of exerting some degree of control over the social relations in which one is enmeshed, which in turn implies the ability to transform those social relations to some degree." William H. Sewell, Jr., *Logics of History: Social Theory and Social Transformation*. Chicago: University of Chicago Press, 2005.
- 82 See, for example, Hal Foster, "An Archival Impulse," *October* 110 (2004), 3–22. See also: Jacques Derrida, "Archive Fever: A Freudian Impression," trans. Eric Prenowitz. *Diacritics* 25:2 (1995): 9–63; Guðrún V. Stefánsdóttir and Rannveig Traustadóttir, "Life Histories as Counter Narratives against Dominant and Negative Stereotypes About People with Intellectual Disabilities," *Disability & Society* 30:3 (2015): 368–380. doi: [10.1080/09687599.2015.1024827](https://doi.org/10.1080/09687599.2015.1024827).
- 83 See Karen Harvey, "Epochs of Embodiment: Men, Women and Material Body," *Journal for Eighteenth-Century Studies* 42:4 (2019): 455–469. See also: Karen Harvey, "One British Thing: A History of Embodiment: Ann Purvis, ca. 1793–1849," *Journal of British Studies* 59 (2020): 136–139.
- 84 Sigurður Gylfi Magnússon, *Archive, Slow Ideology and Egodocuments as Micro-historical Autobiography: Potential History*. London: Routledge, 2022, 117–143.
- 85 Stefánsdóttir, *Bíbí í Berlín*, 124.
- 86 *Ibid.*, 135.
- 87 *Ibid.*, 108.

### 3 The First Thirty Years in Berlín (1929–1958)

Bíbí's first 30 years are a most interesting time. Icelandic society had not yet made much progress with regard to understanding the circumstances of people with disabilities, nor provisions for them. This is clearly manifested in all aspects of her life, both within and outside her home. Hence a highly interesting opportunity arises for exploring the circumstances of people who essentially had nowhere to turn with regard to their daily needs. Bíbí's family paid little attention to her needs, the community around her had no understanding of her situation, and the "experts" – the physician, clergyman, and teacher – condemned her to a certain ostracism by their diagnosis of her impairment. The result was that she was subjected to what we call "slow violence," a concept that is explained in the chapter.

#### The Stage Is Set

##### *Hofsós*

Bíbí was christened Bjargey Kristjánsdóttir on 2 January 1928.<sup>1</sup> She was her parents' first child and lived with them in Hofsós for the first two years of her life. In 1929 the little family moved into a cottage, Berlín, just outside Hofsós, where Bíbí grew up and lived until her adult years. She was always known as "Bíbí in Berlín," although she was not happy with that name. She remarks: "I always disliked that name after I became older and wiser," but she offers no further explanation.<sup>2</sup>

In the 1930 census of Iceland, the population of the island was 108,861. In the county of Skagafjarðarsýsla, where the village of Hofsós is situated, the population was 4,007, of whom 1,430 had the right to vote. The county recorded 17 blind persons, four deaf, and five "feeble-minded," which was the medical term used at that time for people with intellectual disabilities.<sup>3</sup>

During Bíbí's girlhood, the district comprised the village of Hofsós (whose name derives from its position at the mouth of the Hofsá River)

and the surrounding rural area. In 1930 the village's population was 182, living in 27 homes, while the rural population was 395, on 62 farms. The population of the district totaled 577.<sup>4</sup> The community's children were taught in an old schoolhouse with one classroom, and in the community center's basement.<sup>5</sup> According to official documents, 12 fishing-vessel operators were resident in the district; this is consistent with an account in the fisheries periodical *Ægir* in 1930, which states that 12 fishing boats operated from Hofsóss and the surrounding area: one motorized decked vessel, and three motorized open boats, each with a crew of 2–3, “when they go out fishing at all.”<sup>6</sup> Fishing in open boats was highly dependent on weather and conditions at sea.

The district also had two carpenters, and one each of the following occupations: a teacher, a midwife, a saddler, a bookbinder, a seamstress, the district physician, a merchant, a cooperative store manager, the pastor, a shoemaker, and a commercial employee. The people in the rural area lived by animal husbandry, supplemented with casual employment in the village. In the 1930s, new harbor structures were constructed at



*Figure 3.1* Berlín – Bíbí's home until the age of 30

*Source:* Photo: Kristjana Agnarsdóttir.

*Notes:* The house at Berlín stood by the sea, with a view over the fjord. Bíbí describes it as follows: “The house stood at the seashore, with a gully at the north. There was a gully to the south too. There were steep slopes to the south and north. There were innumerable gullies everywhere. The sheepshed was near the house. The cowshed adjoined the house, with a doorway between. Later another entrance was made.”

Hofsós, mainly with a view to developing a herring fishery there.<sup>7</sup> The coastal freight and passenger vessel *Esja* regularly called at Hofsós on its way around the coast.<sup>8</sup>

The district physician was somewhat optimistic about the state of affairs at Hofsós in his annual report to the Director of Health (*Landlæknir*) for 1930. However, he noted that a devastating cold had swept through the population in the village in January and February, and nine villagers had contracted pneumonia. Five villagers were newly diagnosed with tuberculosis that year, and four were diagnosed with gonorrhoea.<sup>9</sup> In 1930, 28 children were born into the world at Hofsós, one of whom was stillborn.<sup>10</sup> At this time, Icelanders were emerging from a plague of infant mortality that had been part of life in Iceland for centuries.<sup>11</sup> Seven people died that same year at Hofsós, including the stillborn child and two infant girls in the first year of life. Two adult men died of disease, and one young man died at the mental hospital in Reykjavík. A woman in her sixties died, but the cause of death is not recorded in the church register.<sup>12</sup>

But life went on in Hofsós and everyday life may be seen as having been a struggle for the majority of the population. The family at Berlín was no exception.

### *The Cottage Berlín*

Icelandic housing changed dramatically in the first decades of the 20th century, especially in villages and towns in the countryside. The traditional turf houses of the old Icelandic farming community gave way to timber – and later urban houses of concrete. The 1910 census shows 370 concrete houses, 4,500 wooden houses, and 5,400 turf houses in Iceland. Twenty years later, the number of concrete houses had risen to 3,300 and wooden houses to 6,600, while the number of turf houses had dropped to 3,600.<sup>13</sup> When descriptions and measurements in public property valuations are examined, a much more complex picture of housing, especially the housing of the poorest in society, is revealed. The housing of the very poorest was invariably tiny and often built from whatever materials were available locally. As a rule the walls were built of turf and stone, and then the gables were made of wood, sometimes protected by some form of insulation. The insulation could be tar paper or corrugated iron sheets. The roof could be either turf or wood.<sup>14</sup>

The first official documentation of the cottage of Berlín is in the 1910 census, stating that the house is a turf building with one wooden gable wall and two semicircular gables.<sup>15</sup> A property evaluation from 1916 to 1918 states that Berlín is a property without farmland, owned and occupied by



Eiríkur Einarsson, a house “of turf and timber with a turf roof.”<sup>16</sup> The ground area of the house was just under fifteen square meters. In the census of 1920, Berlín is described as a turf house, while the census of 1930 describes it as a 26-year-old wooden house.<sup>17</sup> The 1940 census states that Berlín is a single-story turf house, about 30 years old, without central heating, electricity, or plumbing – i.e., no indoor water supply, WC, or bathroom.<sup>18</sup> It was a hybrid form of a wooden and a turf house. Official documentation of Berlín is consistent with Bíbí’s description of the house and the conditions there:

I have mentioned before that my parents bought a little shack out by the sea; it stood almost on the seashore, except that there was a high slope in front of one of the house gables and a concrete shed at the other end or gable, there was a cowshed and a midden nearby, of course. ... Indoors, there was a relatively small kitchen with a little narrow window, but the kitchen and bedroom had been one space before. Cooking had been done in the basement under the house. In our time, chickens were kept in the basement, and there was a loft where various things were stored ... Leading off the kitchen was the bedroom; there was room for a bed and chest of drawers and a table, and another bed if necessary, and clothes hooks behind the chest of drawers [...]. In those days, we used oil lamps, and I do not remember whether the kitchen lamp was a 10-line one or more, but I think the parlor lamp was 15 lines or more. That is the way it was then.<sup>19</sup>

Berlín stood at the seashore with a view out over the fjord. Bíbí gives the following description of the position of the house:

The house stood at the seashore, with a gully at the north. There was a gully to the south too. There were steep slopes to the south and north. There were innumerable gullies everywhere. The sheepshed was near the house. The cowshed adjoined the house, with a doorway between. Later another entrance was made.<sup>20</sup>

As Bíbí’s account implies, conditions in Berlín were poor, with little personal space. Bíbí, of course, had no private space for herself during her time in Berlín, and she often refers to these penurious conditions and her lack of personal space. It must be borne in mind that four people occupied the 15 m<sup>2</sup> home. This was much less space per person than the majority of people had at their disposal. For example, housing statistics show that in 1940 the average two-room dwelling was inhabited by 1.72 persons.<sup>21</sup>

*“The Peculiar Attitude of the People”*

In her infancy, Bibí was considered a promising child, but she fell ill just before his first birthday and became “something strange and not like normal.” She was sent to the doctor for tests. She was not expected to survive the illness, but she did! Bibí says she did not start walking until she was about six years old. She was classified as “feeble-minded” by her family and neighbors, and hidden away from strangers. Bibí shares her recollection of her family’s attempts to conceal her existence:

I was not allowed to be outside if guests passed by, often in bright sunshine and fine weather. I can tell you a story from when I was probably around nine. Two girls arrived one morning; one was related to Mum and me. I cannot recall whether they were offered coffee, but, anyhow, I was the victim of the peculiar attitudes of the people and had to hide in the dark corner by the stove while they stayed. If this peculiar attitude had involved making me go inside when guests arrived or when someone was travelling on the road, it would have been a different thing. However, when my father was not at home, I could be anywhere I wanted. He was ashamed of me because I was disabled and looked different from other children, that’s for sure.<sup>22</sup>

During Bibí’s upbringing and adolescence, social discrimination and prejudice toward people with intellectual disabilities were widespread, especially if they were considered intellectually challenged. It was not uncommon for children and grown-ups with disabilities to be isolated in their homes or concealed, as in Bibí’s case.<sup>23</sup> In her autobiography she often mentions “the peculiar attitude of the people,” as she does above, when describing negative actions or attitudes toward her.

While such attitudes colored Bibí’s early life, rural life suited her well enough. She loved the country around her, and the nature and animals were to her liking. She writes that animals were her best friends and companions – not least the cats:

There had been many cats in our home, all belonging to the same tribe. I clearly remember the first kitty, a tabby, about the same age as me. When she grew up and started having kittens, my parents eventually replaced her with one of them. This dear old tabby was a very clever specimen, and once she came to my mother and seemed very miserable. My mother had no idea what was wrong until she brought her one of her kittens which had died. This was what she wanted to tell my mother. Is this a brute animal? I certainly do not think so.<sup>24</sup>

Bíbi recounts growing up in severe poverty; as an example, she mentions that the lack of weatherproof clothing prevented her from being outside: “I wanted to be out of doors when the weather was good, but not when there was a storm, and that meant that I had no overgarments – nothing but some thin sweaters. I had a coat, admittedly, but that was of course only for best.”<sup>25</sup>



*Figure 3.2* Bíbí’s parents

*Source:* Kópavogur District Archives. Photographic archive of Áslaug Gunnsteinsdóttir and Ólafur Jens Pétursson.

*Notes:* Bíbí’s parents, Guðrún Mundína Steinþórsdóttir and Kristján Júlíus Guðmundsson. The identity of the photographer is uncertain, but it may well have been Sigurpáll Steinþórs-son, Bíbí’s maternal uncle. The photograph may have been taken around 1940. Bíbí was subservient to her mother, but had a stormier relationship with her father, who appears to have had difficulty accepting her impairment, and to have been ashamed of her.

Bíbí writes extensively about the clothes she possessed, and she had her own views of what she wore while having little influence. She was often sent clothes and other things by her family, especially her maternal grandfather, paternal grandmother, and maternal aunts. The autobiography includes entertaining accounts of the parcels she received and the clothes she wore:

What she [Granny] sent me was only sometimes suitable, often in dark colors like a kitchen skivvy might wear, sitting all day over the hearth, surrounded by peat smoke and other filth. With my dark hair, I should rather have been dressed in light colors. Though some clothes were made for me apart from that, I wasn't allowed to wear them until I went to the Christmas party.<sup>26</sup>

However, she never mentions hunger or a lack of food. She takes a considerable interest in food, and her story presents numerous interesting descriptions of culinary culture and the daily diet, as illustrated by the example below:

At home, our regular diet was blood pudding and milk porridge, milk soup, on rare occasions sweet soup or rice soup, and sometimes bread soup; twice a week, we had meat soup on Sundays and Wednesdays. Often stew was prepared from leftovers, especially on Mondays. Otherwise, fish was often served, both pan-fried and boiled, and fishballs were made from haddock. The stomachs, liver and heads of cod were also eaten. All of this was good food, but the meat soup upset my digestion and always gave me acute diarrhea. Sometimes we had *skyr* [milk curd], and my problem was severe constipation which caused me great discomfort.<sup>27</sup>

Bíbí's descriptions of the Berlín family's dietary habits and choices align with other contemporary sources. The daily diet was relatively simple but changed in step with the seasons and varying success in the fishery, depending on weather conditions. A special effort was made to make thorough use of all organic matter and food scraps.<sup>28</sup>

Bíbí describes the positive and negative aspects of her relationships with other children from neighboring farms. In some cases she was accepted as an equal, but on other occasions she was teased or ignored. Bibí describes these characteristic interactions: "My childhood was anything but pleasant; this was because of 'the peculiar attitude of the people'; it is wrong of grown-up people when they pretend not to notice that their children are bullying and teasing a person with a disability. That is a nasty attitude to have."<sup>29</sup>

**Within the Walls at Berlín***Emotional Communities*

Emotion can shed light on power dynamics, social norms, and identity constructions within societies. Emotions are not solely individual experiences but are shaped by social and cultural forces. Exploring emotional communities and the changes in emotional attitudes over time provides valuable insights into social structures, ideologies, and power relations.<sup>30</sup> This is important to keep in mind when we look at the life of B́ibi in Berlín.

In 2002, Barbara Rosenwein, a professor of Medieval History at Loyola University Chicago, wrote a landmark article in the *American Historical Review* titled “Worrying about Emotions in History.” The most remarkable aspect of Rosenwein’s article is the introduction of her own contemplations and definition of the concept she calls “Emotional communities.”<sup>31</sup> This concept is further developed in her subsequent articles and writings over the following years and serves as the foundation for her book, *Generations of Feeling: A History of Emotions 600–1700*, published in 2015. Barbara Rosenwein’s theory and her definitions of emotions, emotional communities, and emotional words can be summarized as follows:

*Emotions* – Everyone possesses an inherent and biological capacity to experience what we call emotions, but the recognition, evaluation, and value attributed to these emotions are socially constructed within specific cultural circumstances. *Emotional Communities* – These are independent, variable, and unpredictable societies that adhere to their own laws and customs. An individual can belong to multiple emotional communities simultaneously. These communities share similarities with “speech communities” that have similar linguistic attitudes at specific times and places. Emotional communities can exist as central or peripheral entities within societies and can even overlap with one another. Studies on emotional life in the past primarily rely on words and word combinations that vary from one emotional community to another.<sup>32</sup>

It is thus necessary to study each in its own right, as every community is subject to its own rules and customs, and that is where the methods of microhistory can prove useful: “There are two points here,” writes Barbara Rosenwein, “not only does every society call forth, shape, constrain, and express emotions differently, but *even within the same society* contradictory values and models, not to mention deviant individuals, find their place.”<sup>33</sup> Here Rosenwein states that historians and others who address the history of emotions must seek to approach delicate subjects of study by other means than those required by the grand narrative. The field of study

must be broken down into small units where one can apply the methods of microhistory.<sup>34</sup> The diagnostic tools of Rosenwein's emotions are systematically employed to analyze Bíbí's emotional communities, shedding new light on her life trajectory from a fresh perspective.

### *Inheriting an Emotional Community*

Bíbí was born into an existing emotional community of her parents and close relatives that was, after all, both dynamic and constantly changing. Bíbí's parents Kristján and Guðrún lived by fishing, along with small animal husbandry described by Bíbí as follows: "There was generally one cow and one horse and sheep, chickens, and one cat, sometimes."<sup>35</sup>



*Figure 3.3* The family at Berlín

*Source:* Kópavogur District Archives. Photographic archive of Áslaug Gunnsteinsdóttir and Ólafur Jens Pétursson.

*Notes:* This is one of few extant photographs of Bíbí as a girl. She is probably 12 or 13 here. Bíbí writes: "One time Uncle Palli [Sigurpáll] came to visit us, he had a camera, they were a rare sight back then, at least I had rarely seen such a thing, I don't know about the others. Anyway, Palli apparently intended to take a picture of us, I don't quite remember whether my mother changed Steini's clothes, but she probably did. I remember I had to take off the skirt and the red sweater I was wearing and put on the damned pink dress I hated. As if that weren't enough, I had to go out with the others behind the barn, and stay there with the weather battering me, as there was a storm at the time, and Palli took pictures of us there. I don't think those pictures were successful, as they were never sent to us, I never saw them, at least."

Due to poverty, the family in Berlín lived a challenging and demanding life. They had, for instance, to rent grassfields from their neighbors in order to provide hay for the livestock. Bíbí reports that, besides farming, her father Kristján operated a small fishing boat, which must have provided a welcome boost to the family economy. Kristján was a local man from near Hofsó, and his parents and sister lived in a house named Brekka, which was within walking distance of Berlín. Guðrún, on the other hand, was from a different part of the country and had no close relatives nearby.

The couple differed in character. Kristján was often away from home, whether at sea or in other work. He had a reputation for being morose and hot-tempered, both at home and elsewhere. He was thus, as Bíbí reports, a difficult person to be around. One never knew how he would react toward people around him; one moment he might be a pleasant man to be around who had, for example, ambitions for the future of his daughter, but at the next minute he started to shout and threaten physical punishment if Bíbí did not do exactly as he told her.

On the other hand, Bíbí's relatives and contemporaries in Hofsó spoke well of Guðrún. She was said to have been a fine woman, very neat and tidy, and good with her hands, but quiet, and she rarely left her home. A Hofsó woman recounted visiting Berlín once, and despite the small size of the cottage, and the poor conditions, the home had been strikingly clean and orderly.<sup>36</sup>

Bíbí often likens her father's rages to storms, remarking that "a northeasterly gale and storm" had broken out in her father. Bíbí also recounts stories about his overbearing and controlling behavior, not least toward her mother, as witnessed the following: "But I would simply wish that he and my mother had never met; she deserved a better man. However, why do men like that get hold of women and marry them? Probably so that they will wait upon them."<sup>37</sup>

Interviews with Bíbí's Hofsó relatives and people in the village revealed that her parents did not fit in with their contemporaries – they had their own emotional community that did not harmonize well with the local community. Kristján was not only regarded as eccentric and temperamental, but he also drifted from job to job, and according to Bíbí his health was also poor. None of these qualities invited a closer relationship with their contemporaries. Arguably, Kristján's character may have led to the family's isolation, especially when Bíbí was young before her brother Steini was born. It may be argued that Steini opened up the family relationship with their neighbors since he took part in the daily affairs of the locals more than anyone else. Their emotional community changed accordingly, but not to Bíbí's liking because she was not a direct participant in those emotional communities. Bíbí's story includes many

detailed descriptions of nature, and at an early age she became enchanted by all sorts of flora, especially small flowering plants in Icelandic nature.

The narrative of Bíbí's upbringing in Berlin is characterized by isolation and profound solitude. She longed for companionship but found it only in nature and among animals. Her own emotional community consisted of cats, chickens, shorebirds, and summer flowers. Bíbí's ability to establish emotional bonds with entities other than fellow human beings flourished during her adult years.

### *The Atmosphere at Home*

Needless to say, family life at Berlín was characterized by both emotional and material poverty, mostly driven by Kristján's complex personality and the family's isolation. He felt deep shame for having fathered a disabled child, and he took that frustrated emotion out on both Bíbí and Guðrún. He often exhibited a great disdain for Bíbí within the home, and would sometimes hurl abuse at her and strike out at her. Guðrún was always gravely concerned about Bíbí and had little confidence in her. However, she also displayed affection for her, which Bíbí reciprocated. Bíbí was, however, severely disappointed in her mother, especially in her adult years. Bíbí was afraid of Kristján and horrified by his behavior toward her and her mother.

Between the parents was underlying tension due to financial pressures and also emotional factors. They were both greatly dissatisfied with their lives, expressed through irritation of various kinds in Kristján's case, while Guðrún was insecure and without support from her own family. As the autobiography indicates, Bíbí had mixed feelings about her parents, especially her father. She recounts that he was ashamed of her and hid her away when guests came to visit. She was also sent to her corner when he was at home. Bíbí has many tales to tell of this nature:

My old man would often flare up for no reason, and even though I had done nothing, he ordered me to shut up and threatened to beat me – and I was like a frightened bird. There was always one thing: I was never allowed to be anywhere if guests came except somewhere in a corner where I would not be noticed. However, when he was not at home, I could be wherever I wanted.<sup>38</sup>

Bíbí describes her parents as having often displayed coldness and a lack of understanding toward her. However, she also expresses love for her mother and experiences undisguised grief when she dies. Even her father had his moments of kindness, recalled by Bíbí: "Sometimes my old dad was nice to me and made toys for me, made houses of turf



and stone, and once he made a wooden dolls' house, for me. Once he made a wooden horse for me.”<sup>39</sup> From BÍbÍ's narrative, one can only conclude that she became, in a sense, a manifestation of her parents' disappointment, and even shame, in bringing into the world a child with a disability.

While BÍbÍ often writes critically about her childhood and the relationship with her parents, she appears to have seen them differently as an adult, and she viewed them as her allies – people who were important for her wellbeing. It is essential to her that they should not be victimized or belittled. Perhaps this later view toward her parents and childhood is a testimony of her powerful desire to belong to others and have a family: BÍbÍ often reports great loneliness and pain over her situation and a desire to have a safe place on her own – to have her own family.

### *Brother Steini*

BÍbÍ had one brother, Þorsteinn, nicknamed Steini, who was born on 26 August 1936, when BÍbÍ was nine years old. BÍbÍ's feelings toward Steini were very mixed, although there is no doubt that she cared for him. She describes him as an inventive and amusingly goofy character, but she also says he is unmanageable, naughty, and mischievous. BÍbÍ recounts in her autobiography that their parents preferred Steini. His status within the family made BÍbÍ feel wretched and jealous, and she attaches various epithets to the boy, such as “the prince,” “the prodigy,” and “the oaf.” BÍbÍ argued:

It was pretty incredible how they pampered this boy. Later, I was to look after the little prince, I was supposed to hold his pacifier, but I could not keep it up. The backs of my thighs became so sore standing there stock-still. It was no better when I was supposed to sit on the floor with the boy; I did that twice but gave up, and then she hit me. Mothers should never do such a thing with their disabled children. However, I will tell you here and now that I would rather have looked after 100 chickens than that little brat.<sup>40</sup>

BÍbÍ was painfully aware of how her parents felt about Steini, and as a result she had strong feelings of rejection and inadequacy. As so often in her account, BÍbÍ hit upon the crux of the matter when she wrote:

They spoiled him rotten, that's for sure. He was a boy, but I was a disabled girl. I know this is not a nice thing to say, but sometimes I felt that all three of them, my parents, and the boy, were like a

pack of snarling beasts. You are always in the way; that is how it was with me.<sup>41</sup>

The following example clearly illustrates the way the parents discriminated between the siblings. BÍbí recounts that when guests came to Berlín, she was sent to the nook, while Steini was the focus of attention:

Then I was confined behind the head of my bed by the coal scuttle while Dad dandled the boy in the guests' faces. It was as if I had two dolls, one old and ugly and the other straight out of the shop and pretty. It is as if I had hidden the ugly doll and showed off the pretty one. Do you understand what I mean? I was the ugly doll. Steini was the pretty one.<sup>42</sup>

BÍbí was often the butt of Steini's teasing. She gives a grim account of menstruating for the first time at 14, with no private life or personal space of her own:

Periods or monthlies or whatever you may call it, I got it when I was 14 years old and was entirely free of it when I turned 50, but it was really a difficult time while I was living at home – that was something. It was no problem during the summer; then, you could go outside and do it there. However, it was a horrible nuisance – those who have it or need the monthlies, such as younger people, know how revolting it is to have it in your clothes – but only women have monthlies. Never mind that. If I needed to urinate, I needed to get rid of it; the boy would prevent me from getting to the pail – there was a pail at home for doing one's business. I sometimes got into a rage about it, shoved the boy out of the way, and said I had to do it.<sup>43</sup>

These remarks reveal BÍbí's intense pain at being so coldheartedly set aside. In her story, BÍbí often brings up how she envied Steini, not only because he received much more attention than she ever did but also because he was allowed to work outside with her father. BÍbí's parents insisted that she help her mother with traditional women's tasks inside the farmhouse, whereas BÍbí wanted to work outside in nature. BÍbí and her father constantly argued about her work participation, and he often hit her or locked her inside the house. She says, "I was often beaten when I protested against washing up or helping Mum."<sup>44</sup>

When BÍbí was growing up, women's place was in the home, cooking, cleaning, and caring for the family. BÍbí did not want to fall into that category. As described, intersectionality theory seeks to understand how

disability and other social categories, such as gender and social class, intersect and lead to oppression and exclusion.<sup>45</sup> Bíbí was not only labeled “feeble-minded”; she was also a girl, and her family was poor and had low social status in the local community. Isolation was their real destiny.

It is clear from Bíbí’s text that Steini exhibited the same kind of disdain for Bíbí as their parents. Bíbí, on the other hand, had very mixed feelings about her brother. While despising him for his behavior toward her, she took pride in him just as their parents did. That applied especially to his manual skills and academic gifts later in life.

Steini also brought a new dimension to the family since his playground was all around in the local community. He brought a certain kind of “normalization” to the family. He was much more accepted within the community, and this social situation highlighted Bíbí’s isolation. She was a teenager when Steini became a factor in the family dynamic, and by then Bíbí’s social status was already established; she was simply considered an outsider and had no escape route. Steini was in this sense a breath of fresh air into the family, but at the same time his own personality confirmed both his parents’ and Bíbí’s social situation.

The emotional community within Berlin was therefore very complex and coercive, and the pecking order was very clear. First and foremost was the father; Steini soon rose above this mother in the pecking order, but Bíbí’s position never changed. It was the lowest and aside from the rest.

### *Diagnosis and the Impact of Being Stigmatized*

In her early years Bíbí was not particularly happy with the medical profession, as she recounts in the autobiography: “In the beginning, when I was young, I was for quite a long time scared of a certain profession; that is, the doctors. I did not want anything to do with them, which was hardly surprising.”<sup>46</sup> Bíbí maintains that she was a promising child. In the summer of 1928, when Bíbí was almost a year old, she lived with her parents in Hofsós. In order to support the family, her father went to work in Siglufjörður, a town close by, while her mother was hired to work on a nearby farm and took Bíbí with her. Conditions on the farm were grossly inadequate and unhealthy. As a result, Bíbí became seriously ill. She describes the consequences of her illness as follows:

I became so ill that people thought I would die, but those who are least liked live longest. That is how it was with me; it would have been better if I had kicked the bucket then rather than becoming flotsam in this world, if I can put it that way – all because of the peculiar attitudes of the people.<sup>47</sup>

The above account reflects Bíbí's sorrow over being marginalized and excluded all her life. In the autumn of 1937, new developments in Bíbí's struggle with the medical profession came about, as described in the following passage from her autobiography:

In the autumn of 1937, my mother took me urgently to Sauðárkrókur [the nearest town]. The following morning the boat reached Sauðárkrókur, but we had to wait for people in town to wake up. I cannot remember what time it was when we met the doctor, probably around 3 o'clock. I did not like the look of that creature – I apologize to my readers for my language! As soon as I, or we, went in there and I saw him, I went wild and scorned him. It probably happened when I was to be undressed, but never mind. The old man examined me from top, but not all the way to toe. After that the stupid old man gave his verdict. I was supposed to be feeble in both ways, that is to say both body and mind, but he was lying. The damned man announced what was wrong with me. I remember my mother telling him I could read when he asked. And he lied that I mustn't eat meat; instead, I was to eat things I had never tasted before, such as dulse and scurvy grass. He seemed to think he could put into me what was missing, but he could not take it from anyone else, the old scoundrel.<sup>48</sup>

In her dramatic description of the medical examination, Bíbí reveals that she has completely lost control of herself and her emotions. Whether it affected the doctor's diagnosis is a question that is never answered. But when they got home, nothing better happened:

We returned home during the night, but we had hardly entered the house when guests asked my mother how we had got on. She told them what the old man had said, repeating all his lies. I was furious about this. I want to say this: Never tell guests what is wrong with your child after taking them to a doctor if it is something particular.<sup>49</sup>

This detailed description of an incident from the distant past, decades after it occurred, is interesting. Scholars have pointed out that memory is closely connected with momentous events in people's lives, both negative and positive.<sup>50</sup> They are more likely to stick in people's memory their whole life. This was probably such an event for Bíbí, one that, in her mind, demonstrated how she had been stigmatized as a deviant and second-class



*Figure 3.4* Cat with Berlín in the background

*Source:* Photographer unknown: The collection of Bíbí – private documents.

*Notes:* Bíbí was very fond of animals, and had a special affection for the cats at home at Berlín.

human being. Bíbí's description reflects her attitude to the highly negative stigma of disability, which she regards as a label that leads to exclusion and negative attitudes. This is especially noticeable in how Bíbí was deeply hurt by her mother telling others about the doctor's diagnosis.

In the Sauðárkrókur district doctor's report to the Chief Medical Officer of Health for the year 1937, the primary diseases occurring in his area are listed under their Latin names, one of which was *Poliomyelitis* or polio. The doctor diagnosed one patient with the disease; this patient was probably Bíbí.<sup>51</sup> When the pastor conducted his regular pastoral inspection in Berlín in 1936, a year before the visit to the doctor in Sauðárkrókur, he wrote in the comment's column that Bíbí was suffering from rickets.<sup>52</sup> Bíbí describes the attempts by doctors and the clergyman to diagnose her illness in the following terms:

My mother had taken me to them all, but to tell the truth, I cannot remember any of them. One thing I remember, though, is that each said his piece of nonsense. One said I had rickets, which was nonsense. Another said I had swollen glands behind the stomach; this was nonsense. Kids who have this grow naturally, and it does not affect them. I know this well now.<sup>53</sup>

Bíbí was probably correct in her assessment. Later in life Bíbí was diagnosed with hypothyroidism, which had probably afflicted her from an early age. This ailment can present several symptoms, varying from fatigue and constipation to stunted growth and intelligence. To prevent this condition, all newborn infants have, for a long time, been screened for this particular disease, which has been virtually eradicated in almost every developed country.<sup>54</sup> The symptoms outlined here are often referred to

in Bíbí's autobiography when she describes herself and her "sickliness," as she puts it. Moreover, she tells us that she was often tired and did not grow normally. This fits with the diagnosis stated in the medical records on Bíbí from her later years, but there are good reasons to assume that her symptoms were mild.<sup>55</sup>

Bíbí does not explain why her mother, Guðrún, took her to Sauðárkrókur to consult a family doctor. This may have been mainly because Bíbí's mother wanted a second medical opinion. In 1937 the year they visited the district doctor in Sauðárkrókur, there was also another available in Hof-sós. Although we cannot be sure, it is possible that Bíbí's parents felt that Hof-sós was too close and that the shame attached to having a disabled child played a significant role in the decision.

### *Education and Reading Lessons*

In 1907, Iceland adopted the first comprehensive legislation on general education.<sup>56</sup> The Act stipulated compulsory education for children aged 10–14 years. Other aspects of children's education were assigned to the home, and they were supposed to be taught to read and write at home before starting school at the age of ten.<sup>57</sup>

This requirement to teach children at home was based on a centuries-old domestic education system whereby the pastor acted as supervisor and examiner. Although the final examinations that were part of the compulsory education system had superseded the educational assessment that had previously been part of the preparation for confirmation, clergymen nevertheless continued to test children's abilities in reading, writing, arithmetic, and biblical knowledge well into the early decades of the 20th century. It is worth mentioning that in Hof-sós in 1938, children were taught in an old school building, with one classroom in the basement at the local community center.<sup>58</sup>

Despite the legal obligation to provide compulsory education, the law also specified that children could be exempted from attending school due to a "lack of intelligence" or illness. Bíbí did not have an opportunity to go to school, and this legal exemption may have played a role. Bíbí describes her feelings in the following way:

Deep down within myself, I have felt so sorry not to be allowed to go to school with my peers. But what of that? There are a few things that peculiar attitudes cannot spoil. In those days when I was ten years old, all my contemporaries had to go to primary school, but I was not allowed to go to school. Instead, they got a girl to teach me after Dad had tried.<sup>59</sup>

This reference also bears witness to “the peculiar attitude of the people,” the negative perspectives that dominated the community in those times. It demonstrates how much it hurt BÍBÍ’s feelings to be denied the opportunities that her peers enjoyed. Nevertheless, BÍBÍ’s father was keen to ensure that she was taught at home; this instruction was carried out by various people, such as her father himself, her grandmother, and girls from neighboring farms, as BÍBÍ mentions above.

Things did not always go smoothly, however, as BÍBÍ recounts in her autobiography. She struggles with her father, as she recounts in the following sentences:

Sometimes my old man lost his patience and told me off while teaching me to read. Once, he slapped me in the face with the alphabet book. Nobody should do a thing like that, least of all hit a weak, disabled child. My granny was a more patient teacher than my dad. Later, they got a girl to teach me. Her name was Guðríður, and she made me read the book of bedtime stories which Aunt Jana had sent me. I could probably read by that time. I never went to primary school, but I took the spring exam and answered questions.<sup>60</sup>

Whether it was the shame of having a disabled child in such a small community that prevented BÍBÍ’s father, or even both of her parents, from allowing her to attend the primary school or their joint decision with the authorities, the impact was dramatic for BÍBÍ. She was deprived of the education she could have received at school and the emotional community offered by being with peers. Of course, it may be assumed that some of BÍBÍ’s peers might have teased her, but the isolation at homemade matters much worse. The decision to prevent BÍBÍ from attending school with her peers confirmed her differentiation from society and also vice versa – the society’s differentiation from her.

Church records show that when the pastor came to inspect the home at Berlín in 1936, BÍBÍ was nine years of age; she knew the letters of the alphabet and could read simple words.<sup>61</sup> Two years later, another pastor visited Berlín, and he gave BÍBÍ the following grades: Christianity v, reading v+, arithmetic v. Here, v – indicates “good,” which is less than “excellent” but better than “poor.” An additional comment accompanies BÍBÍ’s entry: “backward.”<sup>62</sup> This comment probably originates from BÍBÍ’s parents because the year before, in 1937, BÍBÍ’s mother, Guðrún, had taken her on the fateful visit to the district medical doctoin Sauðárkrókur. With information from her parents about BÍBÍ’s physical and mental condition, the pastor’s label “backward” was here to stay, until BÍBÍ’s death.

### *Confirmation*

With the Reformation in Iceland in the 16th century, it became the duty of pastors to test their parishioners' knowledge of Christianity, as mentioned above. This role became more comprehensive as the centuries went by. Gradually it expanded to include all general education of children in reading, writing, and arithmetic. This educational process was completed with confirmation into the church at around the age of 14, after which they were regarded as adults. Certain conditions had to be fulfilled for a child to be confirmed, the most important of which were having been christened, learning the necessary subject matter, and having reached the age of 14 years.<sup>63</sup>

Confirmation was arguably the most crucial milestone in a person's life during the period under consideration and children's access to the adult world. Only in the Education Act of 1907 was the status of a complete high school examination established in law. Still, the symbolic value of confirmation as a coming-of-age ritual persisted well into the 20th century.<sup>64</sup> Confirmation was, in other words, a significant event during Bíbí's youth and seen as a ticket into adult life. It marked an important transition in most people's lives when those who were confirmed became a member of the world of the grown-ups. In many instances they left home for work and became a domestic servant, often far away from their parents. For many, this was the beginning of a new life. That was not the case with Bíbí.

It was customary for the pastor in the parish to summon prospective confirmands to him on several occasions before the confirmation, in order to check their knowledge of what they were expected to know in reading, writing, and Christianity. Bíbí was allowed to attend these confirmation classes, and she was so unfamiliar with her immediate surroundings that she had to be escorted back and forth. Her escort was the same age as Bíbí and her name was Anna Andrésdóttir. Bíbí liked Anna a lot. She called her a ray of sunshine and said she was "like a sunny summer day."<sup>65</sup>

On 8 July 1941, Bíbí was confirmed in the local church at Hof, and the clergyman wrote in the church record that both her knowledge and conduct were "Excellent."<sup>66</sup> It is of particular interest, however, that Bíbí was confirmed alone. In contrast, her contemporaries, eight boys and three girls, had been confirmed together at least a month earlier, on Whit Monday.<sup>67</sup>

Based on Bíbí's autobiography, there appears to have been no doubt whether she was to be confirmed. Although she did not attend school with her peers, she began confirmation classes with them when she was 13 years old. It would appear that right up to her confirmation day, Bíbí and her family thought she would be confirmed with her peers. It was thus a bitter disappointment to her when she was excluded. In her autobiography, Bíbí tells us that her mother went to Siglufjörður to buy clothes for the



confirmation, and she describes the day when the group was confirmed in the following manner:

Yes, if only it could have been like that. On Whitsun morning, I, of course, wanted to join my peers. Mum started dressing me in fine leggings and a suspender belt. Then my old daddy urgently had to go to the village before noon, and when he returned, he said he had spoken to two honorable gentlemen: the Reverend Guðmundur and Bragi, the district doctor. He said he had asked both of them whether they thought I was fit to go to a particular ceremony with my peers, and apparently, the pastor said “yes”, but the doctor said “no,” and his opinion decided the matter. This was the news my old dad brought back. In those days, it never occurred to me to be suspicious of anyone. I was upset to miss attending church and being unable to join my peers, and I started to cry. Everything was ready; Sigurlaug á Þönglaskáli had done my hair, and Anna Páls had set it in waves.<sup>68</sup>

One can easily imagine the young girl’s shock, helplessness, and disappointment. Bíbí also indicates in her story that when she was eventually confirmed alone a few weeks later, she was not impressed by the ceremony; no doubt recent events played a significant role in her perception.

At first, Bíbí probably thought that the sequence of events on the confirmation day was because she had been ill with a cold a few days earlier, although she had recovered on the actual day of the confirmation. However, Bíbí later realized that the real reason was different. Once again, she blamed “the peculiar attitude of the people” or the negative mentality of the time, which had so often spoilt her childhood and would continue to do so for the rest of her life. The fact that she was barred from participating in the community of her peers during the confirmation ceremony underscores her parents’ and others’ determination to separate her permanently from society and sentence her to the isolation she truly experienced during her years in Berlín.

These two decisions, preventing Bíbí from schooling and having her confirmed alone, shaped her self-image for life. However, it shows her admirable tenacity to allow it only to bend her, not break her fully.

## Next Door Neighbors and Close Relatives of the Berlín Family

### *The House Brekka*

The sources indicate that Bíbí and her mother rarely left their home. There were, in fact, only three nearby households with whom the family was in regular contact. Brekka is adjacent to Berlín. When Bíbí was born,

her paternal grandmother (and namesake) Bjargey Kristjánsdóttir (1881–1970) was employed as housekeeper to an aged, divorced carpenter, Jakob Símonarson, who owned the house at Brekka and the surrounding land. In addition to Jakob and Bjargey the elder, Brekka was also home to Guðmundur, Bíbí's paternal grandfather, and her paternal aunt Margrét, with her husband and sons. Jakob Símonarson's contemporaries regarded him as a hard man and awkward to deal with. Jakob died in 1935, in his seventies, having been bedridden for a decade.<sup>69</sup> Bíbí was then eight years old. Jakob had bequeathed his assets to Bíbí's aunt Margrét. The reason for this is only partially apparent, but according to Bíbí this had something to do with the arrangements for Jakob's care. The agreement involved Margaret naming her eldest son after Jakob to get the house Brekka. The boy named Jakob Brekkmann was a year younger than Bíbí.

Bjargey at Brekka, the grandmother, appears to have done her best to assist the family at Berlín. Bíbí tells, for instance, many stories of her grandmother giving her clothes and fabric for sewing garments – though Bíbí was not always appreciative, as stated above. Local people recalled that Bjargey at Brekka had a reputation as a diligent and hard-working woman and loyal to her people.<sup>70</sup> In addition, she was a book lover who read extensively.<sup>71</sup>

Bíbí's paternal grandfather, Guðmundur Guðmundsson (1872–1943), features only rarely in the autobiography. However, Bíbí remarks that he was a frequent visitor to Berlín and that he co-owned a fishing boat with her father that they operated together. Bíbí writes of his death:

I was about 14 or 15 when he died; he had been ill for quite a long time before he left this world. ... I cannot be sure whether I was fond of him or not, he would sometimes tease me, and he acted as if he did not like my doll.<sup>72</sup>

Bíbí had mixed feelings about her grandmother, Bjargey the elder – as she did about all her paternal family. Bíbí was, for instance, not happy about being named after her grandmother; according to Bíbí, this was not least because she blamed her grandmother for her illness in her infancy. It is clear that there was not much warmth between Bjargey the elder and Guðrún, her daughter-in-law.

Bíbí did not enjoy the times she visited Brekka. She did her best to keep a low profile, as she was scolded if she did anything to attract attention – especially by her parents. “I did not enjoy going to Brekka; you had to be like a wax doll there, sit in the corner and never smile – let alone be allowed to laugh. It was not the Brekka folk's fault, but my parents' fault.”<sup>73</sup>

Bjargey and Guðmundur at Brekka had six grandchildren: Bíbí and Steini at Berlín, and Margrét's four sons, who also lived at Brekka. So Bíbí had four cousins, all younger than she was and closer to her brother Steini in age. Bíbí states that Jakob, the eldest of the boys, was sometimes her playmate when they were very young, while the younger brothers joined forces with Steini in provoking and teasing Bíbí. As the years passed, their harassment escalated, and Bíbí recounts an attempted rape by one of the cousins:

Now I must tell you that one day the people were not home; I was home alone and was outside, not expecting anyone, since the people were not home. However, it turned out differently. When I had been outside a good while, the boy came and tried to have his way with me. I tried to refuse or stop him from doing it, and finally, I managed to drive him away. When the people came home, I told them about it. The parents did not like what they heard and believed me, but Steini did not believe me and said I was lying, but I said I was not lying; it was true.<sup>74</sup>

Although Bíbí's parents believed her account of the rape attempt, there is nothing in Bíbí's text to indicate that the case was dealt with against the perpetrator. He was not held accountable for the violence he perpetrated. This is where the intersections that characterize the lives of women with disabilities, past and present, shine through. They are not only women but disabled, and are in many cases more exposed to all forms of violence, especially within family relationships.<sup>75</sup>

Bíbí often refers to the people at Brekka as a single unit, and sometimes even includes her brother Steini among them, as he spent much time with them. She was not offered access to the emotional community that her brother Steini had with the Brekka people.

#### *Families at Naust and Þönglaskáli*

Adjacent to Berlín was Naust, a classical Icelandic turf house. Head of the household was an elderly widow, Helga, who had her brother and sister living with her: Ólafur and Sigríður. Sigríður, known as Sigga, was intellectually disabled, and according to Bíbí, she was capable of little work beyond bringing in water and mucking out. Bíbí liked the family at Naust, who treated her kindly. The family was related to people on nearby farms, and that was how Bíbí came to know her friend Alda, who was Helga's grandniece, the daughter of her nephew. Alda was four years younger than Bíbí, born on 18 March 1931. Her parents were Jóhann Eiríksson, a farmer and fishing-boat operator at Þönglaskáli, and

his wife, Sigurlaug Einarsdóttir.<sup>76</sup> Jóhann owned the farm. The house at Pönglaskáli was one of the first concrete buildings in the Hofsósdistrict (*Hofhreppur*).<sup>77</sup> Their social standing was solid, much stronger than the family at Berlín enjoyed.

Pönglaskáli was home to Alda's parents, her paternal grandmother, and Alda's two brothers. Alda's father had grown up in the house at Berlín, and he had sold it to Kristján, Bíbí's father, but with no farmland. Bíbí's account illustrates a significant difference in social status: not only was the extended family connected to Naust more prosperous than Bíbí's in every way, but they also had a far older connection to the place. The families of the two friends came from opposite ends of the social spectrum. Again, Alda was born and raised in a concrete house owned by her parents. The father managed his fishing boat and had people working for him. Bíbí, on the other hand, lived in a small shack, and her father, Kristján, worked as a day laborer in the village, in both agriculture and fishing. It was a relatively short distance between Berlín and Pönglaskáli, and despite the difference in social status, there appears to have been significant contact between the two families. Bíbí describes her friendship with Alda:

We had similar temperaments, both relatively quiet souls, me, and that girl. I got to know Alda better, and I do not regret that acquaintance. I liked her; we never quarreled during those years of friendship but enjoyed playing together in peace. I felt sorry for Alda and thought she was having a rough time. No doubt Alda also felt I was having a rough time, mainly because of the peculiar attitude of the people. I am sure it was not the custom at Pönglaskáli to hide Alda away when guests arrived.<sup>78</sup>

Bíbí reveals more than once that Alda did not have to experience the same isolation and hardship at home that Bíbí endured. Alda even got permission from her parents to visit Berlin:

I hope no one laughs at me when I officially state in this book that I loved Alda as I would have loved my sister if I had had any. We played with my doll and other things. It never occurred to us to try to control each other; that was out of the question. We never slandered anyone, we called nobody names, and we did not tell lies about anyone. We just talked about our things and interests.<sup>79</sup>

In this quotation and many others, it is evident that Bíbí and Alda were equals and formed an important emotional community during their childhood years. Bíbí's memories of Alda from those years are

shrouded in a warm glow. Bíbí describes Alda coming for a visit to Berlín delightfully:

I remember that if I knew Alda was down at Naust, I waited in high expectation, hoping that she would come and visit me, and I was so happy when I saw a fair head appear over the hilltop at Naust farm, then perhaps a red coat appeared and finally all of her. I waited excitedly until she came through the gate between the homefields, and I often stood near the gate until she came to me. This was my Alda, physically disabled from birth but she could nevertheless run incredibly fast, considering the circumstances, and she was brave – this was probably what kept her going.<sup>80</sup>

According to Bíbí, they were close confidantes. As the above piece reveals, Alda had a disability from birth, which may have contributed to their mutual understanding and empathy for each other. Bíbí does not indicate the nature of Alda's disability, and official documents contain no suggestion that Alda was different from other children. For example, she attended the primary school in Hofsó, whereas Bíbí was absent. The social status of their parents may be a factor here, and Bíbí's words may be taken as an indication of this when she says, "... it was not the custom at Þönglaskáli to hide Alda away when guests arrived."<sup>81</sup> The two friends' happiest times were when they were together at Naust. They were able to play together there, undisturbed and in peace, in their early years. This would later change, and Bíbí blamed her brother Steini. Bíbí portrays Steini and Alda as absolute opposites, and she says that she loved Alda like a sister. Alda attended Bíbí's confirmation, and Bíbí was allowed to go to a spring celebration in the primary school to hear Alda sing. After Alda was confirmed, she stopped visiting Bíbí at Berlín, and Bíbí appears to have blamed herself for the end of their friendship. She felt that her role had been to be Alda's protector. One may consider whether that related to the difference in their ages or Alda's apparent physical disability.

As Bíbí and Alda grew older, Bíbí's parents' opposition to their friendship grew. Both her mother and father made derogatory remarks about Alda in Bíbí's hearing, and Steini took an active part in defaming Alda in front of Bíbí. After confirmation, Alda was able to go away and learn to play a musical instrument, which became a big issue for Steini:

I was furious when the boy Steini started calling the instruments names, especially the instrument Alda was learning to play. It is now, and so it is, that I thought Steini thought himself a more remarkable

person than Alda was. I heard that tone, or I thought I heard it. I told the boy that Alda was more of a person than him when he was calling her names, and I was right there, but that [is] another story. I will say it here and tell you the truth: it was my most painful experience to hear my friend being abused.<sup>82</sup>

It seems to have been first and foremost BÍBÍ's father and Steini who finally contrived to ruin BÍBÍ's and Alda's relationship, and BÍBÍ grieved for her friend very much. In the end the family had deprived BÍBÍ of the emotional community that had nourished her the most from early youth.

### *Maternal Aunts*

BÍBÍ reports considerable interaction with her maternal family, especially her aunts and their children. BÍBÍ's maternal grandfather, Steinþór Þorsteinsson (1874–1953), features to some extent in the autobiography; her maternal grandmother, Kristjana Jónsdóttir (1873–1911), had died long before BÍBÍ was born. Steinþór lived in the town of Ólafsfjörður, some distance from Berlín. According to BÍBÍ, he visited Berlín several times when she was growing up. She says he also sent her brother Steini clothes and toys and their parents various domestic items.

BÍBÍ's maternal aunts, Kristjana (Jana, 1900–96), Ólöf (Óla, 1905–84), Anna Lilja (Anna, 1906–80), and Jónína (Ninna, 1906–98), feature in BÍBÍ's story. She also refers to her maternal uncle Sigurpáll (Páll, 1903–1985). Initially, Óla and Anna lived in the town of Siglufjörður, not very far from Berlín; Anna later moved south to Reykjavík, where Jana also lived. As a child, BÍBÍ would visit them in Siglufjörður with her mother, and they often visited the family at Berlín, not least in order to help their sister Guðrún in the home. BÍBÍ believed their assistance had been necessary for the family at Berlín, especially her mother: "Some things would have been rather strange if Aunt Óla and maybe the other aunts had not come to the rescue."<sup>83</sup>

It was Jana and Óla who were most important to BÍBÍ emotionally. Jana was very good at sending gifts to her niece from Reykjavík, both a teddy bear that was not quite suitable for BÍBÍ, books, after BÍBÍ had learned to read, and fabric for sewing garments. Jana was a member of the Seventh-day Adventist congregation and was very active there. BÍBÍ's father despised this congregation, as reflected in BÍBÍ's text. When Jana offered to sponsor Steini to study at the congregation school, the father and Steini absolutely refused to accept the offer. However, BÍBÍ respected her aunt and seemed to have got along well with her when they met. Jana was a great lover of animals, and BÍBÍ certainly appreciated that.

Óla was the one who visited most often, and Guðrún and Bíbí also visited her in Siglufjörður. Bíbí loved her aunt Óla and longed to have a closer relationship with her:

I often wanted to talk to my aunt Óla while she was alive and in full swing, like when she was visiting our house. I wanted to tell her how I was doing, but I would have had to talk to her privately and preferably outside somewhere. It was one thing to speak to her, but it would have been no use talking to the others, Jana, and Anna; they wouldn't have believed anything I'd said, they would have believed what the other people had said, I mean what the other people back home would have told them. But Óla was not fooled; she also visited us more often.<sup>84</sup>

However, Bíbí never mustered the fortitude to disclose her emotions and familial circumstances to Óla. It is conceivable that such an act might not have yielded positive outcomes, given the prevailing atmosphere of indifference toward Bíbí within the household.

The aunts would sometimes express their disapproval of the conditions in which Guðrún and her children lived:

It may be said of Jana that she was unhappy with our accommodation, but that could not be changed, there was not much space, but it was pointless to complain about it – at least for us, who lived with it. I would have liked to have a room of my own sooner than I did. I overheard Jana calling our home a “stable” or something like that.<sup>85</sup>

The aunts were inclined to extend their assistance in alleviating the distress of their siblings. Bíbí discerned and comprehended this inclination, yet at the same time she stood up for her mother when confronted by the aunts, particularly when they broached the family's destitution and adverse circumstances.

## Adult Years at Berlín

### *The 1950s – Slow Violence and Microaggression?*

Bíbí lived with her parents until her early thirties. She writes about those years, among other things, in a chapter under the heading Toil and Distress (*Basl og bágindi*), which sums up Bíbí's life during this period. She reports that her parents and Steini maintained that she was difficult, lazy, and a burden on the family: “They assiduously tried to tell them [the aunts] that I was difficult and so on, and also that I did nothing, and also



*Figure 3.5* Kristján Júlíus outside Berlín

*Source:* Photographer unknown: Regional Archives of Skagafjörður – collection of Jakob Einarsson.

*Notes:* Bíbí’s father Kristján lies at his ease outside the house at Berlín with a sheep. In the background are outhouses of turf and rocks. The windows are unglazed, and covered in the traditional way with a translucent membrane.

that I was clumsy. However, they never said that they were difficult with me, oh no.”<sup>86</sup>

Bíbí describes her difficult conditions at Berlín; she was not trusted to carry out household tasks, and there was no work for her in the village “that could be done by people like me – but I am diligent by nature.”<sup>87</sup> It is probable that, as the years passed and Bíbí grew older, her circumstances at Berlín became even more burdensome than before. In time Bíbí grew more unruly and needed more space. However, she recounts that there was plenty to keep her busy in the summer months, as outdoor tasks suited her better than indoor ones, and she could work all day without getting tired.

Berlín appears not to have been a pleasant place to live in at that time, but Bíbí loved to sing, had a good sense of humor, and could easily see the funny side of people and issues. She writes: “I do not know what would have become of me if I had not been cheerful by disposition. I was not allowed to smile, let alone laugh. Have you ever heard such nonsense?”<sup>88</sup>

Much in Bíbí’s story indicates that she was creative: she enjoyed embroidering, drawing, and painting, but as with so much else, she says that her interest was repressed, so she pursued it secretly. Bíbí’s life was thus dull and monotonous. At this period, her father was still banishing her to the nook when guests visited, and their relationship appears not to have improved.



Bíbí's description of her 30th birthday in 1957 is vivid and gives a good indication of the situation in her home in Berlín:

Of course, it was July 27th for everyone, or what should you say, in their time and place. I don't remember getting any party and I got few gifts. I got a carved shelf from Gógó and those people, and then Óla gave me panties and socks, but they were so fine I couldn't use them. Aunt Jana sent me money, but I did not see it or did not see a penny of it. She sent it in a letter to my mother, and she put it in a savings bank, together with money that had been sent to her, and she put it in her own name in the savings bank. The money I received as a confirmation gift at the time, from people who wanted to cheer me up, that was kept by my mother, was used by her to pay a fee to the women workers' union.<sup>89</sup>

It seems as if Bíbí learned at this time that her mother had used for herself the money that Bíbí had been given as gifts from relatives, and she describes her feelings toward her mother and her family years later.

I was lost when I heard about it; it hurt me so much that I can hardly tell you. I wonder what would have been said had I done that. Either been shamed or beaten, or both. I would never have treated my daughter this way, whether she had been disabled or not, had I been a normal mother. I guess no one would have believed it, least of all the aunts. People with disabled children, please never take the money you are keeping for your children. Whether they are disabled or not, it is not honest.<sup>90</sup>

The implication of Bíbí's account of her adult years at Berlín might be characterized as "slow violence." American literary scholar and environmentalist Rob Nixon coined the concept in his 2013 book *Slow Violence and the Environmentalism of the Poor*. He links it to the impact of dramatic and impending climate change on the world's vulnerable population. Slow violence is a stress condition not usually associated with literal physical violence. It is constantly present, lies behind the scenes, and has a breath of impending disaster unrelated to a particular time or place.<sup>91</sup> Bíbí's narratives of her experiences during adulthood in Berlin exhibit indications of a heightened state of stress. This persistent aura of impending catastrophe had a deleterious impact on her emotional well-being.

In addition, Bíbí's circumstances may be linked to the concept of "microaggression," which is one manifestation of ableism.<sup>92</sup> Both concepts, i.e., slow violence and microaggression, refer to harassment, such as recurrent negative behavior and remarks constantly experienced in their daily lives by

people with disabilities. In other words, because microaggression and slow violence are “perpetrated and experienced subtly and often unconsciously, the victim often questions the reality of oppression.”<sup>93</sup> Diving deeper into the documentation of the outcasts’ lives – in this instance BÍbí’s life – often gives researchers the opportunity to see the topic from a new perspective, as we have sought to do in this book. The autobiography recounts BÍbí’s experience as she was somehow swept off the path of ordinary life, and frequently forced to contend with the day-to-day struggles of existence from the sidelines in her own home. Telling her stories presents an opportunity to draw attention to the more serious side of her situation and daily life, which seems to have been frequently characterized by casual or slow violence and bullying. The autobiography gives us an opportunity to consider whether this mistreatment amounted to a culture of violence and bullying, that essentially empowered the majority to target people who were different, as BÍbí certainly was. All of BÍbí’s daily life was characterized by a lack of confidence in her because of the cultural norms of the time and, at best, negligence, but often downright resentment and irritation. The family in Berlín blamed BÍbí for all kinds of incidents in the home. She was always in the way. She was either ordered to stay inside or to do something. She was said to be lazy, and what she contributed to housework was not appreciated at all. Her distress and isolation were exacerbated as she went along.<sup>94</sup>

BÍbí’s mother, Guðrún, certainly provided her with shelter, as far as she could in the difficult circumstances. No doubt she had her daughter’s interests at heart and worried about what would happen to BÍbí when she was no longer there. BÍbí, however, saw things differently when she recalled her mother’s words:

Once, I heard my mother talking to a neighbor woman, saying she wished I might go to heaven before her. I heard her say that, in the adjacent field, and was very surprised – I was 24 years old. Now as I write this, I am 58, and I am pleased in some ways that my mother did not get her wish, for another role has been allotted to me, that is for sure.<sup>95</sup>

Here we see one of the features of slow violence, i.e. a persistent aura of impending catastrophe unrelated to any particular place or time. These were circumstances which BÍbí herself had no way of escaping. The main difference between slow violence and microaggression is that with microaggression, the individual perceives small and minor events that significantly impact their mental well-being, as they experience such harassment recurrently and sometimes many times a day. Slow violence, on the other hand, may not be evident at the time, but in retrospect, it becomes obvious. This covert abuse affects especially marginalized social groups.<sup>96</sup>

As stated in the introductory chapter of this book, attitudes grounded in eugenics and genetics remained dominant in the 1950s. These views and understanding led people with intellectual disabilities worldwide to be institutionalized and excluded from participation for much of the 20th century. Institutions were generally established in the countryside or on the edge of an urban community.<sup>97</sup> In Iceland, the institutionalization of people with intellectual disabilities took place later than in most other Western societies; in the 1950s, the institutionalization of people with disabilities was commencing in earnest in Iceland. The role of all such institutions was, by law, to take care of the “feeble-minded,” each in their way. People placed great confidence in doctors and specialists, and as stated above, parents and family members were urged to send their children with disabilities, and also adults with disabilities, to one of these institutions.<sup>98</sup>

Bíbí states in her autobiography that when she was in her twenties, the district physician at Hofsós had offered her parents a place for their daughter at a children’s home in “the south.” This was probably a reference to a newly established institution for the “feeble-minded” in Kópavogur, close to the capital, Reykjavík. Bíbí resisted: “I said no; I was angry at the offer; I was angry because I found it so humiliating. I was over twenty, and no idiot, and not a horse, or a sheep, that needed foddering. Apart from that, I wanted to decide for myself what I did about it.”<sup>99</sup> This is precisely the autonomy that eluded Bíbí throughout those years: the ability to independently determine her fate.

### *When Everything Changed*

The year 1958 was fateful in Bíbí’s life, as her mother died suddenly after a brief illness. According to Bíbí, her mother had been under a lot of stress during the winter. She both took work in the village and also did all the housework:

Earlier in the day, she had been wiping her dresser, and everything seemed normal. In the evening, when milking starts, after a specific time, she comes in and tells Steini to go out to the cowshed to help my dad milk, turns off the radio and lay down on the couch I slept on. As time went on, she started vomiting. Of course, I was in there, but I wasn’t quick enough to go for a container, so some things went on the floor, and I had to wipe it up. Dad sent Steini off to a doctor, and he came immediately with Steini.<sup>100</sup>

The district medical doctor at Hofsós, Guðmundur Þórðarson, was relatively new to the profession and was coming to Berlín for the first time in

this critical hour. He could do nothing to save Guðrún's life, and she died before midnight on 26 April 1958. It is interesting to note that relatives from Brekka did not attend to help out, but a woman from a considerable distance was brought in to lay out the body.

Before it was done, I was forced to bid her farewell by kissing the hands of the dead. I felt belittled by this; only kids are expected to do this if someone passes away in the house, either grandma or grandpa.<sup>101</sup>

After that, Bíbí's life was totally transformed. Nothing was as it had been. She says that she vaguely remembers the next few days, but it is clear that the mother's body remained in the house. Bíbí's maternal aunts, Óla, Jana, and Anna, came to Berlín after her mother's death to help in the house and with



*Figure 3.6* Funeral of Bíbí's mother

*Source:* Kópavogur District Archives. Photographic archive of Áslaug Gunnsteinsdóttir and Ólafur Jens Pétursson.

*Notes:* The casket of Bíbí's mother, Guðrún Mundína Steinþórsdóttir, outside the house at Berlín. She died in 1958. While Bíbí was not always happy with the treatment she received from her mother, she was her only source of care and security. After her mother's death, Bíbí's life was turned upside down, when she moved to a different community to live in a retirement home at the age of only 30.

the funeral preparations. Anna brought the casket and the pastor visited to hold a small Christian ceremony – a wake – outside the house in Berlín.<sup>102</sup>

The wake: It took place a few days later, I had never been to one, and I refused to be present at the ceremony; I do not care who blames me if they do not understand. Nobody in our household had died before, so I was unused to all the fuss and bother. Moreover, there was another thing: – if I wanted to shed a few tears, I wanted to do it alone and not in front of strangers because there were other people there, as well as the aunts.<sup>103</sup>

In these paragraphs, Bíbí portrays herself in a situation that is almost unbearable for her. Often, she had been paralyzed by discrimination and rejection, but now uncertainty and hopelessness were added.

### *The Intrigues of the Maternal Aunts*

Bíbí had had a fairly positive opinion of her aunts. After the death of her mother a new period of her life commenced in which they played a considerable role. Something made the aunts hurry to get her out of her childhood home at the earliest possible opportunity. In a chapter called *Secret Talks and Secret Meetings* (Leinimakk og leinifundur) in her autobiography, she describes what happened in the days between the wake and the funeral. The aunts told Bíbí that they were using the time to meet acquaintances in the village:

They had not been meeting the acquaintances but had been seeing Guðmundur Þórðarson and brewing a charming act there. ... The next day ... Jana spoke to me and said that I should go south to Kópavogur to a good home there, where everyone would be nice to me. I haven't forgotten how much I hurt. I started crying and said I'd rather be in a normal home; they had said it was a boarding school. I said I would never go there, and I have stood by it; it was no boarding school; it was an institution for the feeble-minded where Jana and Guðmundur were going to lock me in. He and Jana should go to Hell!<sup>104</sup>

It seems that another attempt was being made to have Bíbí admitted to the institution in Kópavogur without telling her openly of the plan. However, she realized what was going on and again resisted with all her force being sent there:

I got angry inside, still didn't say anything, I wanted to throw something at my aunts most of all, but I didn't, I guess you can't do everything you want to do. ... I'm going to say that I've never intended to

work with idiots, whether Jana is going to read this or not, I'll let it go. I will not have alleviated my frustration about this nonsense they invented, Jana and Gudmundur, and let those aunts understand that I was serious about not going to this paradise they were offering. When they heard my animosity, they began to say that I was being difficult for my family and they thought I would submit once I got south. What nonsense and lies, I say now, it was the family that was difficult for me, but not me being difficult for them.<sup>105</sup>

Bíbí won that battle, but she felt everyone had failed her, and she never forgave her aunts:

I'm not going to talk about this any more now, but I should tell you the truth: I had no business being either in a retirement home or in an institution for the feeble-minded. What I wanted to do was live independently; I could do that just as well as go crazy in that den of idiots. I wanted to live in a regular home and told my aunts, yet they said people would just be nagging me there. Still, the nonsense, what assurance did they have? I would have been nagged at just as much in that den of wolves, and had I been given an apartment where I could have lived in an ordinary way, no one would have nagged me but myself. I asked these good aunts if I could get a room for myself in this grand home, but they said I would have to share a room with another woman there. I felt like saying I didn't want to, they could go and stay there instead of me.<sup>106</sup>

Again and again in her writings, Bíbí reiterates how angry she was with her aunts, especially with Jana, for having her sent away. Bíbí wanted to live with her aunt Óla after her mother's death, and she felt disappointed that she did not have a better relationship with her aunt and enjoy her protection. Bíbí's narrative expresses regret for what might, in her view, have been. Once more, Bíbí encountered the dissolution of an emotional community that had provided sustenance, coinciding with her most profound sorrow – the loss of her mother.

### *The Funeral and the Aftermath*

Guðrún, Bíbí's mother, lay dead in her casket in Berlín for almost a week before she was buried on 6 May 1958, 11 days after her death. One can imagine the tense atmosphere in the tiny cottage by the sea in those early spring days. The aunts sat and argued and whispered on and off and then tried, jointly or separately, to reason with Bíbí, who was beside herself with grief, anger, and fear of her coming fate.

The church and cemetery were situated at a considerable distance from Berlín and Hofsóss, and the family had not anticipated that Bíbí would

attend her mother's funeral. While Bíbí appeared to accept this arrangement, she experienced emotional distress from not being permitted to confront her grief in solitude. Against her will, the aunts enlisted the assistance of a local woman to keep her company during the ceremony in Berlín.

The day following the funeral, Óla departed for her home in Siglufjörður, and subsequently Anna followed suit. Anna carried a message from Guðmundur, the district physician, destined for Blönduós. Bíbí evocatively narrates her understanding of this correspondence in the chapter of her autobiography titled “The Aunts Depart” (*Frænkurnar fara*). She remarks: “When Anna departed, she carried a letter to the post office to Blönduós, addressed to Mr. Páll Kolka. I must reiterate that, in my view, this letter was entirely unnecessary, and would better not have been sent. A few days later, Mr. Guðmundur returned and conveyed that accommodation was available for me. ... What a plot!”<sup>107</sup> Guðmundur Þórðarson swiftly arranged for Bíbí to be accommodated at *Hælið*, an institution in Blönduós, just two weeks following her mother's sudden and tragic demise.

### *Bíbí's Material Inheritance*

Bíbí's utter loneliness and powerlessness at this challenging time is evident in the possessions she was allowed to bring from her father's house, and what was left behind. Her Aunt Jana seems to have had power over the belongings. Bíbí was permitted to have three of her mother's dresses, but not the dress she wanted – a light-brown dress with white roses. According to Jana the dress seemed too refined for Bíbí and her future home.

Bíbí was not allowed to bring two pairs of woolen stockings, nor a small cardboard box that had been her mother's, but she did not stop until she was allowed to bring her bed quilt. Jana felt it was unnecessary to take the quilt. She insisted that Bíbí could get blankets at *Hælið*. Bíbí writes: “I said no and said I owned the quilt and would take it with me, and I did too.” Jana made no objection to Bíbí being allowed to take with her the carved shelf that Aunt Gógó had given her for her birthday less than a year before.

Bíbí's story includes poignant accounts of leaving her girlhood home and district. While she wrote her autobiography long after that event, her account of that transition in her life is vivid and moving. One can imagine her anguish and sorrow at that moment.

Bíbí wanted to say goodbye to a few neighbors, especially Alda and her parents, but she had no opportunity to do so:

I was stunned by this time. I had no heart to say goodbye to the cows and sheep. I thought it would overcome me, especially Hatta – she was a black-headed mare that belonged to my father. The only

animal I said goodbye to was the poor kitty, and I didn't feel able to do so until I realized I must, I never saw that kitty again. That kitty had been my friend, though I didn't always understand her.<sup>108</sup>

While Bíbí had not always been happy at Berlín, it had been her home. Moreover, the only safe place she had known was lost forever. Bíbí, the lover of nature and animals, thus bade farewell in her heart and mind to all that was important to her, knowing little of what the future might hold.

### **From the Autobiography – *Bíbí in Berlín***

#### *Kópavogur Institution*

*I was to be placed, against my will, in a boarding school in Kópavogur, which upon closer inspection was an institution for retarded people. I was not to be informed about what kind of institution it was; it was simply said to be a school for people who had fallen behind in their education. I wasn't really behind in my education in a certain sense, at least academically, even though I didn't attend elementary school. I learned embroidery at the next farm, both flat and contour stitching, and crewel work, but I never learned cross-stitch. It was quite foolish to think that I could start learning when I was 30, there at the Kópavogur Institution, and it was utterly embarrassing. It probably wasn't book-learning that was taught there, I guess it was some kind of handicrafts. My family was so sure that I would end up there, they said that I would be made to work there as soon as I arrived in the south. However, I never intended to go there and resolutely said that I would never go there; I never went south to Kópavogur to be placed in an institution for the feeble-minded there. It might have been by chance that there was a vacancy at Hælið on the 4th floor, or was it by chance that the woman who was in room number 2 happened to pass away? How come the newspaper found its way into my room? I remember it was more likely Þjóðviljinn than Dagur, which snuck onto the bench I slept on, and then an old phone directory, which came later and where I read that Kópavogur Institution was an institution for the feeble-minded. I have the answer; it was because people thought I couldn't read and write, but they were wrong. However, I can never describe how much I detested being at Hælið; I felt superfluous there, and what was a 30-year-old person doing among 70- and 80-year-old people.<sup>109</sup>*

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## 4 Stuck in an Institution (1958–1974)

After her mother's death, when Bíbí was about 30 years old, she refused to move to the capital of Iceland and be placed in an institution for people with intellectual disabilities. Instead, she moved to the nearby town – Blönduós – where she was placed in a retirement home, *Hælið*. She remained there for the next 17 years; these dramatic changes in Bíbí's life are discussed. She did not belong, of course, among the elderly residents, and she was not happy there. But the characteristic feature of Bíbí's life is her resourcefulness, and what she was able to achieve within her circumstances, and that is the subject of this chapter.

### The Great Transition (May 1958)

#### *The Trip from Berlín*

The car journey from Berlín to *Hælið* left a permanent mark on Bíbí's memory. She provides a detailed account of her voyage from Hofsós to Blönduós, which she recalls with a mixture of profound apprehension and light-hearted wit. Bíbí vividly remembers feeling overwhelmed and unable to bid farewell to her neighbors, including her grandmother and namesake. Significantly, Bíbí's narrative underscores the notable absence of the Brekka family during these pivotal days; they appeared not to be involved in the preparations for the funeral and were conspicuously absent during Bíbí's departure.

Bíbí's father recruited a young local man, as Bíbí put it “to transport Jana towards her home, but me to jail.” Following a midday meal, her belongings were loaded into a Willys jeep. Dressed in a brown skirt and a polka-dotted blouse, with a red sweater and parka layered over it, Bíbí bade farewell to her father and brother. She expressed discontentment with the well-worn old shoes she was expected to wear:

The journey commenced, and within an hour, my home disappeared from view. As we proceeded, we reached a point where the Hofsá

river meets the sea. The journey was largely uneventful until an unforeseen incident occurred, though not a car crash. Instead, a wayward rooster encountered an unfortunate fate, as it was ill-equipped to navigate vehicular traffic. The rooster met its demise, and the jeep's driver felt compelled to inform someone about the incident. Following the driver's return, the journey continued without further mishaps.<sup>1</sup>

The journey from Hofsós to Blönduós transpired without any intermediate stops, ending at *Hælið*. Bíbí lived there for 16 years until she moved out and rented a room, owned by her friend, and helped Ingibjörg Sigurðardóttir. Subsequently, she established her household, determined to avoid further institutionalization.

At Blönduós, Bíbí took hesitant steps away from her childhood home, where she had spent her entire life, entering a wholly unfamiliar terrain. The location appeared outlandish, and the premises bore a striking resemblance to a castle compared to her parents' modest, or poor, dwelling. It was as though Bíbí had stepped into an entirely different world upon her arrival in Blönduós. There is, at least, no denying that at this juncture Bíbí and her life faced a direct threat, given the profound sense of isolation that enveloped her. It was as if Bíbí was alone in the world, this was such an overwhelming change in her entire life.

## A New Beginning

### *The Town of Blönduós*

Although Blönduós is only about 100 kilometers from Hofsós, a vast geographical and administrative divide separates these two Icelandic towns. Situated in the northwest region of Iceland, they fall within distinct counties: Hofsós in Skagafjarðarsýsla and Blönduós in Húnavatnssýsla. The historical backdrop reveals an enduring tradition of intense regional rivalry between these two counties.

In 1960 a national census was conducted, revealing that the population of Iceland had surged to 175,680, marking an increase of nearly 70,000 since 1930. Húnavatnssýsla county, comprising west and east parts, had a total population of 3,616. In this context, Blönduós ranked thirtieth among Iceland's 57 most densely populated areas. Blönduós had 597 residents in 135 households. Meanwhile, Hofsós was home to just over 300 people. The population of the capital city, Reykjavík, was just under 72,000.<sup>2</sup>

During this period, the inhabitants of Blönduós were transitioning swiftly into the modern era.<sup>3</sup> The town served as a key transit point along a major highway, becoming a popular destination and overnight stop

for travelers moving between different regions of the country. Notably, Blönduós hosted diverse industries, offering employment opportunities for both men and women that surpassed those found in most parts of the capital area.<sup>4</sup> The residents of Blönduós harbored ambitious aspirations and displayed an unusually optimistic outlook regarding the future of their community.<sup>5</sup> While more than 250 individuals were employed in various industries within Blönduós, only eight derived their livelihoods from fishing, which was usually low for a town of this size.<sup>6</sup> Arguably, Blönduós was first and foremost a service hub that was the center of commerce and trading for the whole region of Húnavatnssýsla.

It is worth noting that the practice of reporting the number of blind, deaf, and “feeble minded” in censuses had declined by this time. Instead, censuses focused on enumerating the occupants and staff of so-called institutional homes, encompassing a variety of facilities such as *inter alia* boarding schools, hospitals, and institutions for individuals with intellectual disabilities, as well as prisons. The 1960 census revealed that in Blönduós were four institutional homes, including *Hælið*.<sup>7</sup> These four institutional homes collectively accommodated and employed 143 individuals, including 57 staff members and 90 residents, with *Hælið* representing the largest among them.

### *Hælið*

As is frequently observed in Iceland, specific individuals have left an enduring impact on the present. Páll V. G. Kolka (1895–1971) was a district physician in Blönduós from 1934 to 1960. A native of the district, he possessed a formidable education and exhibited visionary qualities. He was known for his poetic and well-crafted prose. Among his diverse interests, architecture held a prominent place.<sup>8</sup> Collaborating with other influential figures, he aspired to establish a district institution in Blönduós – *Hælið* – combining hospital services, maternity care, and a retirement home. The overarching vision was to provide comprehensive care for the district’s residents from birth to old age. Páll was pivotal in advancing this project, contributing innovative ideas for a spacious and architecturally striking edifice with futuristic amenities.<sup>9</sup>

*Hælið* is a grand and imposing structure that harmoniously complements the distinctive landscape of Blönduós. It is situated on the cliffs along the banks of the Blanda River, from which the town derives its name. The building’s exterior boasts a white façade and a striking red roof, reminiscent of 19th-century Scandinavian palace architecture. The facility’s construction surpassed expectations, and the entrepreneur Páll Kolka took immense pride in its realization. In an extensive article published in the county’s provincial journal, Páll meticulously reviewed the

architectural history and comprehensively described the interior and exterior features of the building.<sup>10</sup>

According to the article, the building's volume exceeds 9,000 cubic meters, spanning four floors and a basement. It is meticulously insulated, featuring double-glazed windows, a noteworthy innovation for a public building of its time. Each floor encompasses a footprint of 650 square meters. The facility houses a fully equipped hospital with a state-of-the-art operating theatre, emphasizing superior ventilation. The building has three elevators, facilitating movement between floors: standard, medical, and specialized food elevators:

The facility includes four separate apartments for its staff. The west wing houses the apartments of the superintendent and the physician assistant, while the south wing provides apartments for nurses, matron and nursing aides. Each doctor's apartment has a separate entrance, while all other staff members share one. Internally, these apartments are situated within the main building, promoting staff convenience and patient safety and fostering a sense of closeness and interconnectedness throughout the institution.<sup>11</sup>

This passage reveals that a significant number of staff resided within the institution while employed there, likely contributing to the atmosphere at *Hælið*. Each floor within the building had a distinct purpose. The first floor featured multiple kitchens with varying functions, a pantry, and a staff dining area. The second floor housed the institute's central lobby, with a reception area, offices, a minor surgery suite, and X-ray facilities. Additionally, the medical director's private reading room was adjacent to an entrance within his separate apartment. The hospital accommodated 31 patients on the third floor, including an operating theater. As described by Páll Kolka, the uppermost floor of the facility houses an additional ward comprising 15 rooms, most of which are designed to accommodate two individuals:

This ward serves as a nursing unit serving elderly individuals and those with chronic health conditions. Within this ward, two rooms have been configured to form a separate small apartment, complete with an adjoining WC equipped with a shower. In addition to these amenities, this ward encompasses a comprehensive set of facilities, including bathrooms, toilets, a sluice room, a pantry, and a spacious storage area designated for residents' personal belongings. It also features a sunlit dining room and, notably, a distinctive gabled *baðstofa*.<sup>12</sup> This area functions as the nursing department's day room, occupying all the end of the south wing. It enjoys abundant natural



light, with windows oriented to the east, south, and west, and includes a generously sized covered sun shelter. The room is tastefully appointed with comfortable furniture, featuring an open fireplace and ambient lighting from ceiling fixtures and wall-mounted lights. Remarkably, this space serves a dual purpose, functioning as the largest residential area within *Hælið* and a versatile auditorium suitable for hosting various services and memorial events.<sup>13</sup>

Considerable attention and resources were invested in creating a fourth floor that exuded an uplifting and inviting ambience. The décor comprises a palette of “comfortable colors,” complemented by pinkish curtains adorning the windows.<sup>14</sup> The choice of furnishings was made to minimize any institutional character. However, it is essential to note that *Hælið* also bears witness to the prevailing zeitgeist and the pervasive practices of the era, marked by a focus on disease management and institutionalization. For instance, the co-location of services for the elderly, patients, and individuals with disabilities was practical and consistent with the norms of the time, as it was customary to house individuals with disabilities within medical institutions and retirement homes, particularly in rural areas where alternative resources were limited.<sup>15</sup>



*Figure 4.1* Héraðshælið (*Hælið*) at Blönduós

*Source:* Photo: Guðrún Valgerður Stefánsdóttir.

*Notes:* The district hospital and residential home at Blönduós, known as *Hælið*. The building is on four floors. Bibí had a room on the top (attic) floor, which housed a geriatric ward/retirement home. In its time the building was regarded as quite magnificent, and one can only imagine the impact on Bibí when she moved from the humble cottage at Berlín into this “palace.”

In his M.A. thesis “Ungt fólk á elliheimilum á 20. öld” (Young People in Retirement Homes in the 20<sup>th</sup> Century), which is written as a part of our research project, historian Atli Þór Kristjánsson comes to the following conclusions:

The findings reveal that the 20th century witnessed a growing trend of institutionalization in Iceland, though this began relatively late compared to Western Europe. Various medical institutions were established during this period, starting in the early 20th century, and intensifying in the 1950s. The first retirement homes, including *Grund* in Reykjavík, were founded in the 1920s. However, there was a subsequent push to institutionalize individuals with disabilities in the mid-20th century. His research confirms a significant presence of young people in retirement homes, especially in the capital city. The exact number of young individuals with disabilities in these homes remains uncertain, although hints of this phenomenon are emerging.

Statistical data from the 1940s to around 1980 indicate that the placement of young people in retirement homes was not uncommon. The 1950s saw a notable peak in the arrival of individuals under 60 at *Grund*, with 153 such cases. This decade witnessed a substantial number of relatively young individuals, even teenagers, living in *Grund*. Similar patterns were observed in the 1940s and 1960s, with at least 65 individuals under 60 in the 1940s (data are incomplete) and 76 in the 1960s. But from the 1960s the youngest age groups began to decline, a trend that persisted into the 1990s, with no arrivals under 40 at *Grund* by then. This suggests that the significant influx of younger individuals, especially those under 40, had subsided by around 1980. Nevertheless, it should be noted that these figures represent arrivals, and some individuals were placed at *Grund* on a short-term basis. The exact number of these individuals with disabilities remains unclear.

The hypothesis is that until the 1950s, when services for individuals with disabilities began to undergo institutionalization, a substantial number of young individuals with disabilities resided in retirement homes. This practice subsequently declined with the emergence of more specialized disability institutions over time.<sup>16</sup>

## Everyday Life at *Hælið* (1958–1960)

### *Chief Physician Páll Kolka Receives a Letter*

The correspondence referred to in the title of this sub-chapter is called the “unnecessary letter,” a term coined by Bibí. The letter was delivered to Páll Kolka, district physician in Blönduós and medical director of *Hælið*, shortly after the funeral of Bibí’s mother Guðrún Mundína, which took place on 6 May 1958. This letter is in the National Archives of Iceland.

It is important to note that the context of this letter should be considered when analyzing its content, mainly because the sender, Guðmundur Þórðarson, the district physician in Hofsóss, had no prior direct involvement with Bíbí until he visited her mother on 26 April 1958. There is no existing record of direct communication between Guðmundur Þórðarson and Bíbí. Thus the letter serves as a valuable historical document shedding light on the family's perspectives, particularly those of Bíbí's maternal aunts, during this critical period.

The letter provides information about Bíbí's background, medical history, and current condition. It mentions that Bíbí was born on 27 July 1927, and up to the age of one-and-a-half years she was seen as like any other healthy child. However, her health deteriorated when she suffered from pneumonia, pleurisy, and a form of nephritis, resulting in an extended period of illness. It is believed that her symptoms of "feeble-mindedness" began to manifest following this illness. Bíbí had not exhibited any pronounced mental health issues, and there had been no visits to her during the four years that the author of the letter, Guðmundur Þórðarson, had been in his current position.

Nevertheless, it is noted that Bíbí had faced physical challenges, including constipation and weakness in her legs, which affect her mobility. She is described as maintaining control over her bowel and bladder functions and being independent in her feeding habits. It is stated that Bíbí had also acquired basic reading skills and could read simple texts and perform uncomplicated manual tasks under supervision. Her demeanor is characterized as eccentric and reserved around strangers, while she exhibits kindness and adaptability in the presence of familiar individuals. On the whole, Guðmundur Þórðarson concludes that Bíbí possesses sufficient cognitive abilities to engage in simple tasks, provided she has the opportunity to work. However, there was an apparent lack of documented work experience, and she had instead received attentive care.

Guðmundur Þórðarson expresses the hope that temporary accommodation can be arranged for Bíbí. He mentions that she is on a waiting list for admission to the Kópavogur Institution for the Feeble-minded, and he emphasizes the urgency of facilitating her placement there as expeditiously as possible.<sup>17</sup>

The analysis of Bíbí provided in the letter reflects the prevailing medical attitudes toward intellectual disability during the mid-20th century. At this time, all forms of disability were commonly viewed as pathological conditions, and individuals with disabilities were often perceived as burdens on their families and society at large. This perspective was accompanied by a charitable approach, whereby individuals with disabilities were expected to express gratitude for the services

they received, in line with what was considered their rightful place in society.<sup>18</sup>

The physician, in his description of Bíbí, adopts a condescending tone. For instance, he describes Bíbí as “the girl,” without acknowledging her age of 30, as having “complete control of her stools and urine, and never loses these in bed or clothes” and being self-sufficient in her eating habits. The doctor’s characterization of Bíbí’s abilities carries a negative connotation. He mentions her proficiency in manual labor, specifically dovetailing, and suggests that her reading ability is limited to “light reading.” Similarly, the doctor’s portrayal of Bíbí’s behavior as eccentric, her tendency to distance herself when strangers were around, and her obedience and kindness toward familiar individuals are presented in a less than favorable manner. It is perplexing that the doctor does not refer to Bíbí’s small stature or her distinctive voice, which had been noted by many of her contemporaries and recorded in medical records.<sup>19</sup>

The doctor’s assumption that Bíbí can perform simple tasks under supervision reflects a longstanding Icelandic societal attitude that emphasizes an individual’s social standing being determined primarily by their capacity for hard work. Idleness and laziness were generally regarded as undesirable traits.<sup>20</sup> The letter concludes with the noteworthy observation that Bíbí’s potential transfer to the Kópavogur Institution remains pending, underscoring the ongoing uncertainty regarding her future.

Interestingly, Bíbí’s own narrative often presents an alternative perspective, and at times appears as a counter-narrative to the dominant official viewpoints, and this is especially evident in her interactions with the medical profession. This approach always centers on the individual and their relationship with their immediate environment in each instance. Consequently, our representation of the past is enhanced and enriched by the smallest of details, as vividly illustrated by Bíbí’s exceptionally detailed autobiography.<sup>21</sup> There is no indication that Bíbí read the letter Dr Gudmundur sent to Dr Páll. Still, her autobiography is truly the counter-narrative of the diagnosis made in the letter.<sup>22</sup>

### *Bíbí Moves In*

It is tempting to sympathize with Bíbí as she disembarked from the jeep and cast her gaze upon the towering walls of the recently painted white “palace,” crowned with a striking red roof. Undoubtedly, it stood as the biggest dwelling she had encountered thus far, surpassing any previous experiences. Bíbí was welcomed by Anna, the matron of *Hælið*, who promptly organized her luggage and ushered her to the fourth floor via an elevator. At this moment, a young girl kindly held

the elevator door open while Bíbí's belongings were being transported inside. Later in life, the girl recalled how Bíbí felt sad and afraid when arriving at *Hælið*.<sup>23</sup>

Upon reaching the fourth floor, Bíbí was allocated a modestly sized room, her possessions swiftly arranged within, and she was left in solitude without much ceremony. Bíbí expressed her sentiments in her autobiography:

I was uncomfortable there, and felt like a caged bird, and I started to cry a little. I can't describe how unhappy and desolate I was there; I was not inclined to engage in reading or any such pursuits.<sup>24</sup>

In a matter of hours, Bíbí's life had undergone a drastic transformation; transitioning from a modest cottage in Berlín spanning fifteen square meters to the sprawling expanse of a 650-square-meter building, on the fourth floor, equipped with modern amenities. Although her living quarters were not spacious, the lofty ceilings and abundant natural light contributed to a sense of openness.<sup>25</sup> On her first evening at *Hælið*, Bíbí was served her dinner in her room, and found the cuisine unfamiliar and unpalatable.

The next morning marked Bíbí's exploration of her new environment, encountering the medical director, Dr Páll Kolka, whom she later affectionately called "the old master."<sup>26</sup> Dr Páll left an indelible impression, initially appearing somewhat enigmatic but growing more endearing as Bíbí became better acquainted with him. While the details of interactions between Páll and Bíbí remain undisclosed, her subsequent attempt to locate the bathroom revealed her disorientation, necessitating assistance to navigate the unfamiliar terrain.

Notably, Bíbí's initial days at *Hælið* were characterized by a conspicuous lack of attention and introduction to the hilly surroundings or her newfound neighbors by the staff. At this juncture she had entered an entirely unfamiliar and alien world, accentuating the profound transition that had transpired in her life. She embarked on a path marked by increased isolation, surpassing any prior experiences of solitude.

### *The Struggle for Anna: Bíbí's Early Days at Hælið*

Upon her initial arrival at *Hælið*, Bíbí experienced a sense of contentment while residing in a private room – a luxury not afforded to her in Berlín. However, it became evident that Bíbí was in the infirmary. This information was seemingly withheld from her, leading to a profound disappointment upon learning that she would not enjoy the privacy she had initially cherished.

This revelation led to considerable distress, prompting Bíbí to express her frustration through tears. Her emotional response was exacerbated when a staff member was dispatched to prepare the room for her new roommate:

There was no chance of that [having her own room]. They brought another couch and another bedside table. I was so upset that I started crying, although it did not do much good, a girl was sent upstairs with sheets and she was supposed to make up the couch. She said I was stupid, yet it was just a lie, I was just upset because I did not get to have my own room. I so wanted to have a room to myself, and a person isn't stupid just because they want to have their own room.<sup>27</sup>

Bíbí's first roommate was a woman named Anna, and they had a relatively amicable relationship. Born in 1883, Anna was significantly older than Bíbí, with a lifetime of labor, most notably at the farm Hof, spanning over four decades.<sup>28</sup> Bíbí and Anna shared a sense of isolation, fostering an emotional community that resulted from their close cohabitation within the room's confines.

During the initial week, Bíbí described a sense of peace and harmony in her association with Anna. However, this tranquility was disrupted with the arrival of Begga, another resident of *Hælið* who was even older than Anna, born in 1875, making her over half a century Bíbí's senior. Begga, like Anna, had spent her life in the service of others, and her presence was met with mutual disfavor.<sup>29</sup>

Bíbí's aversion to Begga was reciprocated, as their relationship was marked by mutual antipathy. Bíbí perceived Begga as intrusive and overbearing, with her most significant grievance being Begga's perceived interference in her relationship with Anna. An altercation between Bíbí and Begga further highlighted their discord, with Bíbí recounting an incident where she was overwhelmed by Begga's bossiness and resorted to crying:

One time I took offence at Begga's effrontery and began to cry, for I did not dare report the old woman, and some girls came up to the loft and asked why. I was going to answer, but Begga broke in, and said there was no need to butter me up, I was stupid, but that was a pitch-black lie from Begga and nothing else. I was within my rights, Anna was my roommate, not Begga's.<sup>30</sup>

In her writings Bíbí often shares light-hearted anecdotes of Begga's interactions with the "old master" Dr Páll Kolka. At that time the medical profession held a revered status within society, a sentiment echoed in Bíbí's

descriptions. She recounted instances where Begga displayed amusing behaviors in her attempts to gain Páll's attention. But Páll Kolka himself is invariably portrayed as dignified and esteemed:

It was funny sometimes when they met in the corridor, old master Páll and Begga. It was Begga who was funny, not Páll, he was always a respectable, bless him. ... He was on his ward rounds, but Begga had to show off and see others, as she would go and stand in front of Páll. I often felt like laughing at Begga when she put herself in that pose and whined in Páll's face. Then she was like a kitten who wants to be petted, and I wished I had a camera, to take a picture of this scene.<sup>31</sup>

Regrettably, Begga's presence strained the relationship between Bíbí and Anna, and Begga made derogatory remarks about Bíbí's physical and mental condition in the presence of others. Bíbí recalled overhearing Begga spreading unkind falsehoods about her to a newly admitted resident at *Hælið*:

One time it was, first after I arrived, it was I think the first summer I was there at *Hælið*. Begga was outside and was talking to a man who had recently been housed there at *Hælið*, I heard them what they were saying. There was nothing nice about what Begga was prattling to the man, she was telling lies about me. I should have reported her yet didn't, more's the pity, but never mind. She was telling this man that I was boring and that I was leading Anna like a dog on a leash. These were the biggest lies imaginable. But I wasn't pretentious like Begga, who always wore a pearl necklace every day, as if it were a queen, Begga was like a snuffbox, shiny enough on the outside, but dirty on the inside.<sup>32</sup>

Anna died two years after Bíbí's arrival. Bíbí perceived Begga's reaction to Anna's decease as emotionally detached and stated that Begga did not attend Anna's funeral. In her characteristic metaphorical and humorous style, Bíbí likened Begga's association with Anna to "a lamprey clinging to a whale," emphasizing the lack of genuine friendship.<sup>33</sup> These expressions showcase Bíbí's unique manner of communication and underscore her unwavering principles regarding friendship and loyalty. Begga herself died just a few months after Anna, leaving Bíbí to witness the demise of both individuals within two years of her admission to *Hælið*.

Bíbí's narrative, detailing her contest with Begga over Anna's affections, assumes particular relevance when viewed through the lens of emotional

community theories. In this dynamic, three individuals were involved, with two contending for the attention and emotional bonds associated with friendship, access, and forming an emotional community. Begga actively seized every opportunity to undermine Bíbí's standing, although Bíbí had the advantage of being Anna's roommate. Notably, Anna did not hold a particularly favorable opinion of Bíbí, as evidenced by her comments suggesting that Bíbí ought to engage in activities such as knitting socks or crocheting. Anna expressed distinct displeasure over Bíbí's utilization of their shared living space for her activities with her dolls.

Indeed, Anna displayed occasional idiosyncrasies, primarily due to her declining hearing. This prompted a degree of caution in Bíbí, as she was reluctant to speak too loudly for fear of inconveniencing Anna:

Yes, Anna was odd sometimes, she was starting to hear rather badly. I found it necessary to speak a little loudly, so she could hear me, but that was no better, for then Anna said I was hard of hearing, which was the most nonsense, for my hearing was good.<sup>34</sup>

The complex and distinctive emotional relationship between Anna, Begga, and Bíbí significantly impacted Bíbí's life, leaving an enduring impression. Bíbí found it hard to forgive Begga's aloof demeanor and offensive remarks, as exemplified in this account:

On one occasion, while I was outdoors, I overheard Begga conversing with another woman on a balcony, I heard every word, although there was a light breeze. I listened to their conversation, which was as follows: The unfamiliar woman asked, 'Who is that person? Is she a resident here at Hælið?' Begga replied, 'Yes, she lives here and is awfully boring.' The other woman queried, 'Is she receiving medical care?' Begga responded, 'Yes, she must be.' Those who may read this account can imagine how awful the woman was. Neither statement was true, that I was boring, or receiving medical treatment. I had been shoved into this home, and I was to be kept there, like a horse in a pen, until I could be shoved into that institution for idiots, but that's another story.<sup>35</sup>

The arsenal employed in the battle for Anna's companionship consisted of words and disparaging comments from Begga's side, met with tears and piercing glares from Bíbí. These derogatory expressions found fertile ground among the staff and fellow residents, leading to the misconception that Bíbí lacked intelligence. Bíbí's narrative is a testament to the profound impact of these hurtful words and comments, highlighting her vulnerability in the face of such verbal onslaughts.



*Condescending Attitude and Bíbí's Resistance*

Bíbí's life at *Hælið* was marked not only by its striking solitude but also by the imposition of stringent institutional regulations and an intriguing blend of indifference displayed by both staff and fellow residents. This peculiar cocktail of apathy ranged from gradual harm and micro-aggression, exhibiting characteristics of slow violence. Throughout her stay, Bíbí confronted disparaging comments and was subject to the erroneous assumption that she lacked basic literacy skills, leading to the unfortunate consequences of these misconceptions.

Many members of staff treated Bíbí with condescension, seemingly convinced she could not perform basic tasks such as reading and writing. A telling incident illustrates this: when Bíbí received a package from one of her aunts, she found that she lacked a pen, a necessity for sending her thanks. Bíbí sought assistance from a nursing aide to obtain a pen, and another maid for an envelope, so she could write her thank-you letter:

I'm going to tell you a story about people's stupidity about what they assumed was my ignorance. One of my aunts sent me a package, but I had no pen then, but I still had to write south to say thank you of course. I then asked one of the girls to get me a pen and asked another for an envelope and to write on it for me, and that was done almost immediately for me. I waited a long time for the pen and a pad of paper, finally another girl showed up with a pen and a pad of paper, I had asked her too. The girl then asked me what to write. I told her she didn't have to write anything, because I would write the letter myself and I did, then the letter was taken down to the post office by someone from the home – but the first thing I asked my aunt for was a pen and a pad of paper.<sup>36</sup>

This incident deeply saddened Bíbí, as it exemplified the misguided belief among her companions that she could not read and write, fueling a slew of unfounded stories about her.

Furthermore, Bíbí grappled with the absence of personal space to store her belongings, a source of frustration, particularly in her interactions with staff members. She discovered a newspaper on her bed one day, an incident that significantly affected her. She immersed herself in the publication and encountered a detailed article discussing the government's new legislation concerning assistance for “feeble-minded individuals” and establishing new institutions:

As mentioned before, it had been decided to send me to a school south in Kópavogur, some special school that was for people who

had fallen behind in education or schooling, it was supposed to be in Kópavogur, a school like that. But when I looked in that paper there was no mention of such things in the paper, no special school for me and people like me, but it listed five institutions for the feeble-minded right there in Kópavogur and two elsewhere.<sup>37</sup>

The newspaper in question was published on Saturday, 29 April 1958, just before Bíbí's admission to *Hælið*. Intriguingly, this specific copy had been intentionally placed on Bíbí's bed, inviting her to peruse its contents. A certain Lóa, who worked at the telephone exchange and as a cleaner at *Hælið*, confirmed to Bíbí that there was no special school in Kópavogur, as she had been told:

I wrote to my Aunt Jana telling her that I would not go to this school and at the same time told her that I had no lockable chest or locker, because these people at *Hælið* could not be trusted. ... I wasn't an idiot. I had no business being in an institution for idiots.<sup>38</sup>

It is noteworthy that Bíbí employs the term *feeble-minded*, a concept that is directly addressed in the newspaper article. The article delves into the administration of intelligence tests and the derivation of IQ scores from such assessments. It explains that psychologists employ these tests to measure general human intelligence, yielding IQ scores anchored around the mean of 100. Individuals whose IQ falls below 75 are characterized as experiencing intellectual deficiency, which can be categorized as abnormal or pathological, referred to as feeble-mindedness. The article further stratifies this into three levels, differentiating by IQ scores: "idiots" (IQ below 30), who have limited cognitive functioning; "imbeciles" (IQ between 30 and 50), whose intellectual development never surpasses that of a 13-year-old; and "morons" (IQ 50-75), who constitute the most populous group within this categorization.<sup>39</sup>

Bíbí's resistance to being defined on the basis of the diagnostic categories discussed in the article is evident, as her medical records contain no indication of her undergoing any form of intelligence testing. The multiple forms of discrimination and stigma that Bíbí endured likely had a profound impact on her self-perception across various life stages. The repercussions of stigma are akin to the process experienced by individuals undervalued, marginalized, and excluded from society due to a misalignment with prevailing norms or perceived "normalcy" at a given time.<sup>40</sup> The effects of stigma can lead to internalization, where individuals who experience stigma begin to perceive themselves through the same negative lens that society employs and may internalize feelings of inferiority. Such internalization can profoundly affect emotional well-being and identity, engendering feelings of distress and hopelessness.



*Figure 4.2* A young woman in a retirement home

*Source:* Regional Archives, East Húnavatnssýsla: from the photographic archive of Sigursteinn Guðmundsson.

*Notes:* Here Bíbí is seen in national costume with other residents of the retirement home. She does not appear particularly cheerful in this photo, and she never felt happy during her years at *Hælið*. In Iceland, young people with disabilities who had nowhere to go were sometimes placed in retirement homes. But this arrangement cut Bíbí off from the outside community, which was a devastating situation.

As Bíbí articulates, “Though I never scalded myself in hot water and so never got any scars from that, I have got invisible scars, and they are the work of people’s malice.”<sup>41</sup> This sentiment underscores the profound impact of societal labeling on Bíbí’s identity. But this example is nuanced, as Bíbí attributes the harm to the cruelty of others, rather than ascribing it to herself or her impairment. It is also evident that she did not consistently internalize the oppression she faced. In her reflections, she elucidates the consequences of disability prejudice and multiple forms of discrimination when she asks: “That is how it was for me; would it not have been better for me to have kicked the bucket then than to be flotsam in this world, if I can put it that way?” Bíbí phrases this idea in ambiguous terms, emphasized by the final, ironical, question mark.<sup>42</sup>

### *Miss Halldóra and Old Brynjólfur*

*Hælið* maintained a unique dynamic characterized by a discernible trade-off between its staff and residents. Among the staff, Medical Director Páll and Anna the matron occupied the highest rungs of the hierarchical ladder. But within the confines of the white “palace” in Blönduós, it was one

of the residents who reigned supreme, uncontested. This resident was a certain Miss Halldóra Bjarnadóttir. Halldóra's charisma held sway over *Hælið's* environment. Before arriving at *Hælið*, she had enjoyed a successful career as a teacher, principal, and the editor of a widely circulated women's magazine. Her transition to the fourth floor of *Hælið* took place on New Year's Eve 1955 when she was 82 years old. By the time Bíbí entered the institution in 1958, Halldóra was 85 years old, 54 years Bíbí's senior. Halldóra's quarters on the fourth floor comprised not just one but two private rooms, along with a storage space, underscoring her prominence and high status within the institution.<sup>43</sup>

Halldóra, despite her advanced age, exhibited remarkable vitality and remained socially active. She was a prolific correspondent and frequently embarked on extended excursions from *Hælið*. Bíbí notes that Halldóra enjoyed a degree of latitude in this regard, while others, including herself, were subject to travel restrictions.

According to Bíbí, her interactions with Halldóra were somewhat limited, except for occasional requests from Halldóra for Bíbí to post letters on her behalf. On one occasion, Halldóra employed Bíbí to organize her correspondence, and Bíbí received generous compensation for her services. Bíbí's narrative reflects Halldóra's substantial presence within *Hælið*, and it is evident that Halldóra contributed articles to newspapers and magazines, providing insights into life on the fourth floor.

In 1970, a brief article by Halldóra surfaced in a district magazine, recounting her efforts to arrange a photography session featuring women in Icelandic national costumes. The accompanying photographs in the article depict Bíbí, among other women, attired in borrowed garments, most likely provided by Halldóra. Bíbí looks far from happy.<sup>44</sup>

A few years after Bíbí arrived at *Hælið*, an elderly man named Brynjólfur moved in. Born in 1875, he was born in the same year as Begga. Brynjólfur had considerable carpentry skills, which he used at *Hælið*.<sup>45</sup> His craftsmanship extended to constructing a dresser for Bíbí, affording her the long-awaited provision of a secure storage unit for her belongings. This dresser served as a source of solace and protection, particularly when Bíbí grappled with feelings of emptiness, often exacerbated by Begga's presence.

Nonetheless, two aspects of Brynjólfur's behavior did not sit well with Bíbí. Firstly, he made unwelcome advances by inviting her to sit on his lap and kiss him after he had shaved "and even though I told him it couldn't be done, the old man just ignored me. It was very unpleasant for me, people blamed me for it, but it was a horrid lie."<sup>46</sup>

Secondly, there was some gossip about Brynjólfur's behavior; Bíbí states that she was told that rumors were circulating that she was engaged to Brynjólfur, who had lost his wife in 1941. "What endless

nonsense, I would never have thought of giving my hand to an old man, and the people who put this rumor about should pay about 8000 *krónur* [Icelandic currency] for their foul mouth, it's not too much."<sup>47</sup> Bíbí found these advances deeply unsettling and felt unfairly blamed by others for the situation despite her vehement rejection of Brynjólfur's advances.

Although Bíbí endured discomfort due to Brynjólfur's inappropriate behavior toward her, she remembered him with gratitude for taking her side against those who reproached her. Additionally, she appreciated his assistance in providing her with personal storage, enabling her to maintain her belongings separately from others.

### *Finding Solace in the Company of Dolls*

Following Bíbí's narrative, it becomes apparent that she had brought three dolls with her from Berlín. Of them, one had been received as a gift, while the remaining two were rag dolls personally crafted by Bíbí. She meticulously sewed clothing for these dolls and diligently cared for them. To fill her time and imbue her life with a sense of purpose, Bíbí embarked on the endeavor of collecting dolls. She decided to acquire dolls occasionally, particularly as her financial situation improved, viewing them as aesthetically pleasing and a source of recreation:

I started buying a doll every now and then, after I started having more money and had them as ornaments and a pastime, but then it was as if I couldn't be left in peace with them, in two ways. Some people were always going on about how I was spending my time, I was too old for that and so on and so forth. I pretended not to hear, but this talk hurt me.<sup>48</sup>

It is evident from the text that Bíbí's doll collection attracted negative attention and elicited disapproving reactions from the residents. She encountered criticism from individuals who disapproved of her continued interest in dolls, deeming her too old for such pursuits. Despite this censure, Bíbí chose to disregard these remarks, as she found them hurtful and questioned the relevance of others' opinions on her interests.

The text also provides evidence that Bíbí's dolls were subjected to mistreatment. On one occasion, she entered her room to discover that her favorite doll had been tampered with, and one of its legs had been removed. This incident left her feeling angry and emotionally wounded, especially considering the doll's relatively high cost when initially purchased. Bíbí attributed this damage to the behavior of her roommate, who would leave the door open when leaving the room, exposing her belongings to

potential harm. Although Bíbí was not responsible for these occurrences at home, she felt powerless to prevent them. In her view, the staff on duty were indifferent to safeguarding her possessions, neglecting to take measures to prevent their being damaged by others.

The instances above highlight certain individuals' peculiar and intrusive involvement in Bíbí's life and pursuits while she resided at *Hælið*. Various individuals held opinions about what activities were acceptable or unacceptable for her. In some cases, Bíbí yielded to external pressures, choosing to dispose of certain dolls that had sparked particular objections in order to preserve the peace and avoid further conflicts.<sup>49</sup>

Bíbí also describes visitors at *Hælið* mocking her and her dolls. When one woman sarcastically asked if there were children living in the home since there were dolls, Bíbí comments:

Moreover, it can well be said here that it was a lonesome person who owned the dolls and enjoyed them, and since the staff and especially the management didn't stop her having them, people who visited the home had no right to be butting in with regard to dolls.<sup>50</sup>

Here, Bíbí understands that for her, the dolls have taken the place of the family she longed to have.

The constant and underlying micro-aggression she suffered is reflected in those memories about her and the dolls at *Hælið*.<sup>51</sup> All the talk, derogatory comments, and laughter became part of the many invisible scars that Bíbí describes so brilliantly. Throughout this phase of her life, Bíbí waged a ceaseless battle for her survival within the confines of *Hælið*, and an imaginary emotional community with the dolls emerged as a sanctuary amid the relentless struggle.

### Bíbí's Advocates (1960–1964)

#### *María from the Farm Bakki*

The interactions mentioned above between Begga and Bíbí, along with the incidents involving Bíbí's doll collection, serve as clear indicators of the harassment and bias that Bíbí endured from fellow residents during her time at *Hælið*. In her autobiography she provides additional examples of such mistreatment. When room number twelve became available following Begga's death in 1960, it was occupied by a couple, María Ólafsdóttir and her husband Tómas. For Bíbí, this marked a notable change in her interactions with other residents.

Significant age differences characterized the couple's dynamic. Tómas, born in 1883, was the same age as Bíbí's former roommate Anna, whereas

María, born in 1903, was two decades younger than her husband and 20 years older than Bíbí.<sup>52</sup> Bíbí recounts their initial encounter, emphasizing the contrast between María and her previous roommate, Begga:

Room number 12 did not appeal to me while Begga reigned there; it felt like freezing weather in a northerly gale – I have already mentioned Begga. No, María from Bakki was different. She did not say to humble folk like me, ‘I want nothing to do with such people,’ as I once heard Begga remark. María, on the other hand, was akin to a sunny summer day, with sunshine and warmth and tranquility – otherwise we would have never have become friends.<sup>53</sup>

As frequently observed in Bíbí’s narrative, her descriptive language vividly depicts her experiences. She highlights how María often supported her when she faced derogatory comments from others. She recounts a specific incident during a shopping trip with María when a woman made a demeaning remark about Bíbí:

While María and I were on our way out of the shop we encountered a woman who said to María, ‘And you have this one with you,’ as though María had a little dog or something. She then added, ‘Can she read at all?’ María’s response to this incident has remained imprinted in my memory. She confidently stated, ‘Yes, she reads and chooses books far more wisely than many people may think.’ The woman fell silent, and we continued on our way. I pondered many thoughts in silence.<sup>54</sup>

This incident wounded Bíbí deeply but highlighted the individuals who stood up for her, as María did. Undoubtedly, Bíbí valued such support, and the text suggests that she experienced a degree of triumph and resistance against the prevailing attitudes of her fellow residents for the first time. This newfound resilience and solidarity gave Bíbí the courage and strength to navigate life within the institution.

María and Bíbí’s relationship did not last long, only three years. Tómas died in 1963 and María moved to live with her children in Reykjavík. Bíbí missed her very much, but there is no evidence that they had any contact after that. Bíbí did not forget María’s kindness and clearly stated that she would remember her for the rest of her life.

### *Björg – The Blessed Dove*

Bíbí adeptly tells her life story to the medical directors at *Hælið* and their respective spouses, some of whom she regarded as her patrons and closest confidants as her life unfolded. Among these individuals of whom she was

particularly fond was Páll Kolka, who was medical director during her first three years in the home. Equally dear to her heart was Guðbjörg (Björg) Guðmundsdóttir Kolka (1888–1974), Páll’s wife, who played a pivotal role in Bíbí’s early years at *Hælið*. It is worth noting that Björg was roughly four decades Bíbí’s senior, and was in her seventies when their paths crossed.<sup>55</sup>

According to Bíbí’s recollections, she was always warmly received in Páll and Björg’s home, and Páll often extended invitations to go out for a drive in his car, or on visits to patients in the surrounding region. These outings not only gave Bíbí captivating tales of the countryside and rural life, as documented in her autobiography, but also provided a welcome break from her otherwise regimented existence. In her own words, Bíbí relished these outings tremendously. It appears that Páll, in his way, sought to alleviate her sense of isolation by including her in his activities. This included inviting her for medical rounds or strolls with their grandchildren. Björg, on the other hand, was a constant source of generosity, regularly bestowing upon Bíbí various treats and gifts, including both dolls and books. Bíbí had a deep affection for her.

The couple’s departure for Reykjavík in 1960 left Bíbí bereft. Björg had been a sanctuary in her life, and their friendship continued to thrive despite the geographical separation. Björg paid several visits to Bíbí at *Hælið*, and the two corresponded. Bíbí sent Björg her poems and verses, and they exchanged Christmas gifts. Bíbí fondly recalls, “At Christmas, I sent Björg the most beautiful Christmas card I could find in the shop to buy. I believed that Björg deserved nothing less, given her boundless kindness to me. And Björg didn’t stop sending me various things after they moved down south.”<sup>56</sup>

In the verse annal Bíbí penned to mark her decade-long residence at *Hælið*, her effusive appreciation for Björg is manifest. She addresses her as a “blessed dove,” a cherished friend, and Bíbí’s deep admiration for her is unmistakable:

When a certain time had passed  
With the same tiresome tug of war  
Came a woman to us and said like this.

She spoke that way.  
I am, she said, Páll’s wife.  
Her voice wasn’t rough.  
She was agreeable and, in appearance, sweet.

I liked her right away.  
And it has lasted to this day.  
That’s where her friendship with me began.  
It was Mrs. Björg, the blessed one.



Then came the hidden one – the sun.  
 I thought it was Christmas time.  
 That’s what your Bíbí says.  
 Goodbye, my dove.

I won’t be tired of it at all,  
 my friend at Bergstaðastræti 81  
 to make a little verse about you  
 that I love and is so good to me.<sup>57</sup>

Regarding these verses for Björg, Bíbí records in her autobiography:

I was so sorry that she left, and I felt twice as bad as before in the home, because I’d lost the haven I longed for. I didn’t like it there, and that’s the truth. I sent various poems and verses to Björg, which I tried to put together myself, and I always ended with a warning that Mr. Páll should not get hold of them. Most of the time, or perhaps always, I also wrote Björg a letter.<sup>58</sup>

The absence of both Björg and Páll from Blönduós, coupled with the subsequent departure of María three years later, left a significant void in Bíbí’s life, leading to a profound sense of malaise. This period also marked a further deepening of her isolation at *Hælið* as she struggled to establish meaningful emotional connections with fellow residents. Furthermore, during this time, Bíbí acquired a new roommate who undoubtedly tested her patience.

#### “A Crazy Roommate”

During her time at *Hælið*, Bíbí experienced numerous changes in roommates, necessitating adaptation to new companions regardless of her personal preferences. She reflects on her feelings of displacement and isolation, considering herself incompatible with fellow residents much older than her:

I can’t ever describe how miserable I was at *Hælið*; I felt I was in the way, not surprisingly. What connection could a thirty-year-old possibly have with individuals in their seventies and eighties, some of whom didn’t understand me? And there was no improvement when, following Anna’s passing, I was assigned a somewhat crazy roommate in 1959.<sup>59</sup>

During this period, Bíbí earnestly expressed her reservations about sharing such close quarters with this individual, who she felt should be in the infirmary. Regrettably, her concerns went unheeded, and as she concedes, “they wanted to shove her in on me because I was not in a position to say no.”<sup>60</sup>

Bíbí goes on to recount various encounters during her more than three-year cohabitation with her “crazy” roommate, which included disturbances to her personal belongings and instances where medical intervention became necessary during her roommate’s episodes. However, Bíbí exhibits a certain level of understanding and compassion for her roommate, acknowledging that between these episodes, the woman displayed pleasant qualities and even engaged in creative activities: “Between the episodes, she could be quite amiable, composing verses, reciting poetry, and singing hymns. I have written poems inspired by her.”<sup>61</sup>

Notably, Bíbí is critical of the placement of a woman with a severe mental disorder in a nursing home, suggesting a potential lack of alternative social programs at the time. Despite her continual reporting of the challenges she faced, there appeared to be limited understanding of her emotional well-being within this context.

Furthermore, Bíbí raises concerns about the responsibility of leaving a partially confused individual with a disabled and vulnerable young woman, implying potential negligence in the institutional care provided. She recounts an incident where her roommate disrupted her sleep, leading to a confrontation:

The other thing is that it wasn’t thanks to *Hælið* that I didn’t go the same way as [my roommate], but it’s a big responsibility to leave a half-confused person with a disabled and vulnerable girl, that could be something to complain of, if you think about it. And once [the roommate] started rolling up her quilt at night and singing to it, and that woke me up and I had trouble falling asleep again. Well, I told her off, and the old woman took offence and said she was putting her baby to sleep and I was waking the child.<sup>62</sup>

This illustrates the profound stress she experienced from continuous, close contact with a person with mental health issues and impairment in an environment where medical and nursing staff were present.

Bíbí’s roommate died in her bed on the night of 4 January 1964. While it remains unclear whether Bíbí was awake at the time, her experience of being in the room with the deceased until the body was removed appears to have had a significant emotional impact. But at least one fellow resident at *Hælið* recognized the challenges Bíbí faced during this period.

#### *Dear Imba – the Savior*

“Dear Imba” played a pivotal role in Bíbí’s life during her stay at *Hælið* and had a significant impact on her overall well-being and circumstances. Imba’s multifaceted role within the institution is highlighted, as she resided

there with her elderly husband while actively participating in the care of the patients.

Her name was Ingibjörg Sigurðardóttir and she would give Bíbí the support and courage needed to change her situation forever. She was born in 1905 and was therefore more than two decades older than Bíbí.<sup>63</sup>

Bíbí could not recollect when she saw Ingibjörg for the first time:

I just remember thinking the woman was so handsome, especially when she was wearing peysuföt [a national costume]. One time I saw her dressed like that, she was coming to a birthday party to someone on the fourth floor, she came with her husband. She was so elegant then, I thought of a queen of diamonds on a playing card, which I had seen some time as a kid.<sup>64</sup>

The exact timing of Ingibjörg and her husband's permanent relocation to *Hælið* remains somewhat unclear, but it appears to have occurred in late 1963. Imba quickly recognized the challenges posed by Bíbí's "crazy roommate" and the emotional toll it was taking on Bíbí. Consequently, Ingibjörg provided invaluable assistance to Bíbí during her roommate's lifetime and was the one to convey news of her death, sparing Bíbí from the burden of delivering this announcement. Ingibjörg also attended the funeral, and her support was instrumental in easing Bíbí's experience during this challenging period.

Importantly, Bíbí did not perceive Ingibjörg as a mere member of the institution's staff but regarded her as a steadfast ally and confidante. Ingibjörg's genuine concern for individuals facing adversity and her willingness to actively engage in their care set her apart. The passage underscores that Ingibjörg's contributions were pivotal to Bíbí's overall sense of well-being and her ability to navigate the challenges she encountered at *Hælið*.

Ingibjörg proved to be extremely kind to Bíbí in every way. One of the first things she did for Bíbí was actually "stealing" her. The Blönduós Women's Institute had organized a one-day outing on Women's Rights Day, 19 June 1964. Ingibjörg was, of course, a member of the Women's Institute, and she asked the matron, Anna, for permission to invite Bíbí along on this trip. Anna refused to let Bíbí go:

Do you know what Imba did? It was funny. She stole me. She met me after she had met Anna and asked me if I wanted to go to Siglufjörður with them. Yes, of course I did, and then Imba told me about her conversation with Anna, but Imba said, "You are going anyway; let us just not say anything to anyone."<sup>65</sup>

This was the first time Bíbí went on an excursion after arriving at the *Hælið*, where she had been for a full six years. She had a wonderful time,

and with Ingibjörg's help, she could visit her maternal aunt Óla and go shopping for books and dolls for her collection. At the end of the chapter on the journey comes a special farewell to Ingibjörg: "Thank you for all the times, dear Imba. I guess that if Ingibjörg had not been there and helped me, I would never have made that trip."<sup>66</sup>

This event was the beginning of a wonderful emotional community between the two friends. Bíbí expresses intense respect for Ingibjörg in the annal, while in the autobiography the relationship is portrayed in more equal terms. This shows how the community between the two developed into a mutual respect between them. They both enjoyed traveling and exploring the country on all kinds of short and long trips over the next few years. It is as if spending time with Ingibjörg filled Bíbí with the strength and courage to deal with her miserable situation at *Hælið*.

After Ingibjörg's husband died in 1965, Ingibjörg stopped working, moved out of *Hælið*, and settled in her own house down in the village. She rented out part of the premises and had some business relating to the company of her only son, the baker at Blönduós. She did not forget her friend Bíbí and continued cultivating their good and fulfilling emotional relationship.

### Heading Into a New Era (1964–1974)

#### *Dr Sigursteinn*

Sigursteinn Guðmundsson was district physician and medical director at the *Hælið* in Blönduós from 1962 to 1999 and said goodbye to the place the year Bíbí died. Sigursteinn often features in Bíbí's autobiography, and as the story progresses, she considers him one of her best friends and benefactors. He saw and understood that Bíbí was neglected, and tried to do what he could to improve her life, especially regarding the diagnosis of her health, which was deteriorating during those years. However, it took time for Sigursteinn to realize what was bothering Bíbí, and it was not entirely his fault.

In the winter of 1964/1965, Bíbí suffered from severe hemorrhoids, which she kept more or less to herself, but in the spring, she decided to see Dr. Sigursteinn:

I went to the waiting room and was going to Sigursteinn, but I still could never find him. There were so many people there that it seemed endless, though I suppose I would have made it had I not been disturbed, and I was both hurt and sad about it, for I felt that it was no one's business but mine if I met with Sigursteinn after the other people had left. Then Mrs. Anna had to come into the

doorway and beckon me to her, and I was silly enough to go. Then she started asking me what I was doing there. ‘See Sigursteinn,’ I say. ‘What is wrong?’, she asks. I tell her what it is. She tells me to come with her; I do. She made some fuss and gave me suppositories and things, but a long time passed and it was no better... Time went on and it was getting worse, like dung in the rain, and one woman was advising me to get it cut out. Well, I thought that might be possible. Imba, or Ingibjörg, whom I have mentioned before, spoke to the High Council [matron Anna] of Hælið about this. Whatever the case, Anna gave up and said that Sigursteinn probably needed to take a look at it.<sup>67</sup>

Matron Anna took on the gatekeeper role and prevented Bíbí from seeking necessary medical care. But happily, Ingibjörg took action to help her friend out; as she was undoubtedly in need of treatment. On 18 June 1965, Dr Sigursteinn operated on Bíbí to free her from her hemorrhoids, and he considered the operation to have been a success beyond expectations. Three weeks later, Sigursteinn wrote the following passage in Bíbí’s medical report:

The patient’s condition has been fine the entire time she has been here. Stools have been removed via a tube, but otherwise they are now returning to normal, and the patient is therefore discharged today and goes to her former place, i.e. to the old people’s unit.<sup>68</sup>

After some time there was a recurrence, and a year later Bíbí had another operation, but it did not help much. She became, in her own words, “powerless and apathetic.”

One time, I could not stand, so I lay in bed all day; after lunch, one of the nurses named Hjördís came and asked why I was in bed. I told her, and she said, ‘You need vitamins,’ and then she was gone; after about 10 minutes, she came back with a vitamin shot and injected me. I think I had 15 injections, and after that I started to feel better, and eventually, I started to be able to go outside. However, it took me a long time to recover from this. Lauga [Bíbí’s then-roommate] could not understand it and wanted me to do something, but I wasn’t about to. Apparently she thought it was faking it, and once, when she came back from seeing Sigursteinn, she started talking to me about it, that she’d talked to Sigursteinn about it, this apathy of mine. And he was supposed to have said it was just hysteria. But my goodness, there was no hysteria about it; I was ill, and limited by this constipation, or whatever you were supposed to call it.<sup>69</sup>

The doctor seems to have resorted to the age-old explanation that women's ill health is caused by hysteria, but the nurse's vitamin injections helped BÍBÍ's health. However, she then became cautious about complaining of feeling unwell, so she would not be accused of hysteria.

Sigursteinn was a year younger than BÍBÍ and was a family man when he took office. It is clear from BÍBÍ's text that she was well acquainted with the medical couple's home, kept a close eye on the children's upbringing and projects, and was involved when they started their families and had children.<sup>70</sup> In the autobiography, BÍBÍ had described Páll Kolka as a respectable but friendly grandfather. But Sigursteinn seems to have been closer to her in every way. She tended to make fun of him, especially when he tried to get BÍBÍ to go on a diet. She quotes many times this verse she wrote about the "diet mania" in Sigursteinn:

Sigursteinn is always trying to get me thinner.  
This fat will not hurt me or my life.  
He must try a different style  
and put Rannveig and Hjördís on a diet.<sup>71</sup>

Rannveig and Hjördís were the members of staff at *Hælið* that BÍBÍ liked the most.

### *The Journey Down South in 1970*

In 1970, BÍBÍ embarked on a significant journey to the National Hospital in Reykjavík (*Landspítalinn*), marking her first voyage to the capital city and her first experience of air travel. She recounted her affliction as having commenced the previous year when her lower limbs began to swell. This was accompanied by a persistent cough, which eventually left her feeling breathless and wheezing, coupled with elevated blood pressure. Initially, BÍBÍ was admitted to the infirmary; but as her condition showed no signs of improvement, she was transported south to Reykjavík for advanced medical treatment. Her autobiography vividly portrays her voyage's captivating narrative, inaugural flight, and sojourn in Reykjavík. When observed from the sky, *Hælið* appeared to her as "a big box with a red lid."<sup>72</sup>

Upon her arrival at the hospital, BÍBÍ was greeted with great enthusiasm by Björg Kolka, a welcome sight that brought her considerable delight. Furthermore, her maternal aunts and their daughters paid her visits during her hospital stay, and her aunt Gógó lent her a book. Shortly after her admission to the hospital, BÍBÍ began to experience an improvement in her health, remarking, "I had not been able to read before because of the cough, but when Gogó left, I attempted to read the book she brought

and, lo and behold, my cough seemed to have been left behind somewhere between Blönduós and Reykjavík.”<sup>73</sup>

Bíbí remained hospitalized for five weeks, during which she underwent a battery of medical tests and examinations. Her narrative suggests that she was prescribed a suitable metabolic medication, resulting in a significant enhancement of her overall health, accompanied by the disappearance of the symptoms mentioned above. A medical letter, dated 21 April 1970, authored by a physician at *Landsþítali* and addressed to Sigursteinn, corroborates this progress, stating, among other observations, that “there was a marked increase in the patient’s activity and even some noticeable change in her appearance.”<sup>74</sup>

Consequently, Bíbí experienced a resurgence in her physical strength, along with an intensification of her restlessness and a heightened desire for self-improvement. She undertook various proactive measures, including the extraction of her damaged teeth and the acquisition of dentures. Additionally, Bíbí and her friend Imba embarked on numerous outings with the Women’s Institute and engaged in independent excursions. Nonetheless, the routine existence within the confines of *Hælið* was on her mind. Her wanderlust led her to explore the urban surroundings more frequently and, more significantly, the picturesque countryside surrounding the town. During one of these excursions, she stumbled upon a place that would hold special significance in her life.

### *Resourcefulness and Practicality*

Bíbí’s resourcefulness and practical insight are admirable when considering her endeavor to transform a cluttered pit containing various detritus – in a no man’s land – into a delightful garden five kilometers from *Hælið*. The toil involved in this undertaking contributed to her mental and physical well-being and garnered numerous expressions of appreciation from those who encountered her efforts. Bíbí narrates how she diligently frequented the garden, weather permitting, daily, commencing when the snow melted in spring and persisting until the first snowfall in fall. In particularly favorable years, this period extended from late April through October, with her commitment to this endeavor spanning close to three decades.

It is noteworthy that Bíbí herself shouldered the responsibility of transporting water to the garden in plastic buckets. A striking image captures her with four ten-liter buckets of water positioned before her. This was a commendable achievement, yet the metamorphosis of the garden itself is equally noteworthy. Vestiges of the garden’s original contours, manifested as raised beds and retaining walls, endure as testaments to her dedicated efforts. Remarkably, the garden’s current appearance leans more toward resembling a cultivated pit than its previous disheveled state.

In a concluding reflection within her autobiography, Bíbí revisits the genesis of her gardening pursuits, suggesting a sense of providence. Returning to this serendipitous situation, one might contemplate the possibility that destiny meant her to spend the rest of her life in Blönduós because of her garden.<sup>75</sup>

### *The Anticipation of Freedom*

As Bíbí's physical strength and vitality increased, so did her sense of restlessness during her residency at *Hælið*, exacerbated by the constant interaction with both staff and fellow residents. She grew weary of certain women with whom she shared her living space, feeling that they exhibited traits or characteristics similar to her own or perhaps emanating from the institution, which she no longer wished to endure. In truth, Bíbí had long been afflicted by a pervasive sense of boredom during her stay at *Hælið*, akin to being trapped in a monotonous routine. However, her experience improved during the summer following the initiation of her gardening project. Nevertheless, one drawback persisted – she was required to return to *Hælið* punctually for dinner, lest she face reprimand or embarrassment for tardiness.

One evening, Bíbí's dear friend Ingibjörg approached her, broaching the subject of her desire for greater independence and a room of her own. Bíbí readily accepted the proposition, though she regrettably failed to keep her intentions discreet, leading to some individuals jesting with her and pretending to leave *Hælið*, questioning her readiness for such a transition.<sup>76</sup>

This episode underscores a recurring theme: while at *Hælið*, Bíbí had no opportunity for personal privacy, as she shared a room with others throughout her stay. The institutional culture of that era enforced strict and regimented rules on the ward for the elderly. Bíbí once again confronted her fellow inmates' doubts regarding her capacity to lead an independent life, using the term “stupid” to characterize their skepticism.

It took some time for Ingibjörg to persuade Dr Sigursteinn and others to grant Bíbí her release from *Hælið*. Eventually, their reservations were overcome, and Bíbí was granted her freedom. Newfound liberty awaited her in the outside world. In a conversation with Ingibjörg Guðmundsdóttir, a nurse at Blönduós during that period, it emerged that both staff and residents at the district asylum harbored significant doubts regarding Bíbí's ability to live independently and care for herself. “Dear Imba” recalled that medical director Sigursteinn questioned Bíbí's ability for self-care. However, Dear Imba expressed complete confidence in her abilities and encouraged Sigursteinn to support her quest to move out of *Hælið* and become an independent human being.



This scenario underscores the prevailing zeitgeist and attitudes toward individuals with disabilities at that time, where Bíbí needed official permission from the director to leave the home. During this period, significant shifts in the treatment of disabled individuals were taking place worldwide, and Iceland was no exception. While Bíbí may not have been fully aware of these emerging trends, it is reasonable to assume that the broader social changes of the era played a role in facilitating her departure from the home. It is noteworthy that in 1975, just a year after Bíbí relocated to Blönduós, Iceland saw the establishment of the first group home in the community for disabled individuals, in Akureyri.<sup>77</sup>

Two women named Ingibjörg played a pivotal role in Bíbí's life by believing in her capabilities. Ingibjörg Guðmundsdóttir, who later moved to Reykjavík, visited Bíbí multiple times and stayed with her. She described Bíbí as a delightful and knowledgeable friend with whom she found great pleasure and reward in spending time.<sup>78</sup> Bíbí reciprocated these sentiments, referring to her friend Ingibjörg as “particularly sweet and kind in attitude.” This reflects a fundamental characteristic of Bíbí's autobiography, wherein she endeavored to acknowledge and express gratitude to all those who had shown her care and respect throughout her life. The other was, of course, Ingibjörg Sigurðardóttir, or Dear Imba, who became Bíbí's best friend and an influential person in the last part of her life. Hence, Bíbí did what few individuals manage to do once they have entered a retirement home; she checked out and started a new life as an independent person.

### **From the Autobiography – *Bíbí in Berlín***

#### *Self-Reliance*

*Was it by chance that Ingibjörg Sigurðar – Dear Imba – decided to work at Hælið and moved there, and that I got to know her? It's like this, one thing leads to another, Ingibjörg was turning 60 and was working at Hælið and started to take an interest in me, something few had done before, except for my dear Björg.*

*I was starting to get tired of being at Hælið. To tell the truth, I had always been bored there and felt trapped, although it was better during the summer after I started my garden. But I still always had to be back at Hælið in time for meals, otherwise, I could expect reprimands and scolding when I arrived late. But what about that. I was thinking whether Imba might have a room available that she could perhaps rent to me, but I didn't dare to talk to her about it. Then one evening, Imba came to me and started talking about it and offered me a room at her house, I quickly accepted. Unfortunately, I wasn't wise enough to keep quiet about this, although, fortunately, there weren't many I told. Some started to ridicule me for leaving Hælið and asked me if I knew what I was doing. About*

two months passed before I moved, and then Imba got a man to move my stuff down there, and he did it efficiently and well. This was around the turn of October - November in 1974. I was in the basement for 9 years, experiencing both the bitter and the sweet.<sup>79</sup>

## Notes

- 1 Guðrún Valgerður Stefánsdóttir, *Bíbí í Berlín: Sjálfsævisaga Bjargeyjar Kristjánsdóttur*. Sýnisbók íslenskrar alþýðumenningar 29. Reykjavík: Háskólaútgáfan/ University of Iceland Press 2022, 222–223, 342.
- 2 *Manntal á Íslandi 1. desember 1960*/Census 1 December 1960, Reykjavík: Hagstofa Íslands/Statistics Iceland, 23, 3–4.
- 3 *Reikningar sveitarfélaga og stofnana þeirra 1952*, Reykjavík: Hagstofa Íslands/Statistics Iceland, 42; Ragnar Jónsson, “Fréttabréf úr Blönduóshreppi,” *Ársritið Húnvetningur* (June 1957): 69–70.
- 4 *Reikningar sveitarfélaga og stofnana þeirra 1952*, 42.
- 5 Þorsteinn Matthíasson, “Viðtöl við nokkra húnverska athafnamenn,” *Húnavaka*, 1 (May 1962): 5–30.
- 6 *Manntal á Íslandi 1, desember 1960*/Census 1 December 1960, 116–117.
- 7 *Ibid.*, 203.
- 8 Sigurður Sigurðsson, “Páll V. G. Kolka,” *Morgunblaðið* (27 July 1971): 10; Páll V. G. Kolka, “Héraðshæli Austur-Húnvetninga,” *Ársritið Húnvetningur* 1956, (1 June 1956): 5–27.
- 9 Kolka, “Héraðshæli Austur-Húnvetninga,” 5–27.
- 10 *Ibid.*
- 11 *Ibid.*
- 12 The *baðstofa* was a feature of the traditional Icelandic turf farmhouse, a communal space where the household slept, ate, socialized, and relaxed together. It often featured a central hearth for heating and cooking and served as the heart of the household. In modern Icelandic homes, the term may still refer to the living room or a similar communal space.
- 13 Kolka, “Héraðshæli Austur-Húnvetninga,” 24–25.
- 14 *Ibid.*, 25.
- 15 Atli Þór Kristinsson, “Ungt fólk á elliheimilum á 20. öld.” [Young People in Retirement Homes in 20th-Century Iceland]. MA thesis in History, University of Iceland. Forthcoming 2024.
- 16 Kristinsson, “Ungt fólk á elliheimilum á 20. öld.”
- 17 Þí. Heilbrigðisstofnunin Blönduósi/Blönduós Health Center, SA/0134.
- 18 Dan Goodley, *Disability Studies. An Interdisciplinary Introduction*. Thousand Oaks: Sage, 2016. See also: Hanna Björg Sigurjónsdóttir, et al., “Inngangur: Rannsóknir á fötlun og menningu.” In H. B. Sigurjónsdóttir, Á. Jakobsson, and K. Björnsdóttir, eds., *Fötlun og menning: Íslandssagan í öðru ljósi*, Reykjavík: Social Science Research Institute and Center for Disability Studies, University of Iceland, 2013, 17. [Disability and Culture].
- 19 Þí. Heilbrigðisstofnunin Blönduósi/Blönduós Health Center, SA/0134.
- 20 Sólveig Ólafsdóttir, *Vald og vanmáttur: Eitt hundrad og einisaga á jafri samfélagsins 1770–1936*. Doctoral dissertation, University of Iceland, School of Humanities, Faculty of History and Philosophy, 2022, 213.

- 21 Guðrún V. Stefánsdóttir and Sólveig Ólafsdóttir, “The Peculiar Attitude of the People: The Life and Social Conditions of the ‘Feeble-minded’ Girl in the Early 20th Century.” In Hanna Björg Sigurjónsdóttir, et al., eds., *Understanding Disability throughout History: Interdisciplinary Perspectives in Iceland from Settlement to 1936*. London: Routledge, 2022, 58–75.
- 22 Guðrún V. Stefánsdóttir and Rannveig Traustadóttir, “Life Histories as Counter-Narratives against Dominant and Negative Stereotypes about People with Intellectual Disabilities,” *Disability & Society* 30:3 (2015): 368–380. Guðrún V. Stefánsdóttir, “*Ég hef svo mikið að segja*,” 124–139.
- 23 Birna Ragnarsdóttir oral interview with Guðrún Valgerður Stefánsdóttir, April, 2022.
- 24 Stefánsdóttir, *Bíbí í Berlín*, 223.
- 25 A family house of 15 m<sup>2</sup> occupied by four people gives a personal space of 3.75 m<sup>2</sup>. A personal space on the fourth floor with additional communal rooms and service areas can be estimated at about 55 m<sup>2</sup>. The personal space has increased 15-fold.
- 26 Stefánsdóttir, *Bíbí í Berlín*, 223.
- 27 Stefánsdóttir, *Bíbí í Berlín*, 226.
- 28 ÞÍ. Manntalið/Census 1950 – Hagstofa Íslands/Statistics Iceland 1963 A/40-1-1.
- 29 “Íslendingabók.is.” Íslensk erfðagreining ehf. and Friðrik Skúlason ehf., <http://islendingabok.is> [genealogy database].
- 30 Stefánsdóttir, *Bíbí í Berlín*, 227.
- 31 *Ibid.*, 229.
- 32 *Ibid.*, 227.
- 33 *Ibid.*, 229.
- 34 *Ibid.*, 232.
- 35 *Ibid.*, 228.
- 36 *Ibid.*, 234.
- 37 *Ibid.*
- 38 *Ibid.*, 235.
- 39 “Ríkisstjórnin styður frumvarpið um aðstoð við vangefið fólk,” *Þjóðvilinn* 89 (19 April 1958): 12.
- 40 Clare Marriot, Caroline Parish, Chris Griffiths, Rebecca Fish, “Experiences of Shame and Intellectual Disabilities: Two Case Studies,” *Journal of Intellectual Disabilities* 24:4 (2020): 490.
- 41 Stefánsdóttir, *Bíbí í Berlín*, 139.
- 42 *Ibid.*, 82.
- 43 Halldóra Bjarnadóttir, “Frá Héraðshælinu á Blönduósi,” *Húnavaka* 1 (1 May 1970): 121.
- 44 Halldóra Bjarnadóttir, “Frá Héraðshælinu á Blönduósi,” 122.
- 45 Pétur Þ. Ingjaldsson, “Mannalát árið 1970,” *Húnavaka* 1 (1 May 1971): 192.
- 46 Stefánsdóttir, *Bíbí í Berlín*, 253.
- 47 *Ibid.*
- 48 *Ibid.*, 261.
- 49 *Ibid.*, 262.
- 50 *Ibid.*, 353.
- 51 Monnica T. Williams, “Microaggressions: Clarification, Evidence, and Impact,” *Perspectives on Psychological Science* 15:1 (2020): 9.
- 52 Íslendingabók.is [genealogy database].
- 53 Stefánsdóttir, *Bíbí í Berlín*, 248.

- 54 Ibid.
- 55 Íslendingabók.is [genealogy database].
- 56 Stefánsdóttir, *Bíbí í Berlín*, 237.
- 57 Er viss tími var liðið/ við sama eindemis ófriðinn/kom á loftið kona/ til okkar og mælti svona. Hún tók þannig til máls/ Ég er, sagði hún, konan hans Páls/ Röddin var ekki hrjúf/ var viðfelldin og í framkomu ljúf. Mér varð vel við hana strax/ og það hefur varað til þessa dags/ Þar byrjaði vinátta hennar og mín/ Það var frú Björg þessi auðnalín. Þegar kom sú falda – sól/ fanst mér vera komin jól/ Það segir hún Bibí þín/Góða besta blessuð Dúfan mín. Á því verði ég alls ekki þreytt/ vinkona mín í Bergstaðastræti 81/ að gera svolítin graut um þig/ sem mér þikirk vænt um og er svo góð við mig. Annal of Bjarney Kristjánsdóttir (Bíbí) – manuscript – Poetry. Private collection.
- 58 Stefánsdóttir, *Bíbí í Berlín*, 237.
- 59 Ibid., 240.
- 60 Ibid.
- 61 Ibid.
- 62 Ibid., 241.
- 63 Ibid.
- 64 Ibid., 243.
- 65 Ibid., 244.
- 66 Ibid.
- 67 Ibid., 254.
- 68 ÞÍ. Heilbrigðisstofnunin Blönduósi/Blönduós Health Center, SA/0134.
- 69 Stefánsdóttir, *Bíbí í Berlín*, 256.
- 70 Ibid., 254.
- 71 Megrunarvesen er í Sigursteini/ Ekki verður fitan mér eða lífinu að meini/ Haga verður hann því öðruvísi/ og megra þær Rannveigu og Hjördísi. Annal of Bjarney Kristjánsdóttir (Bíbí) – manuscript – Poetry. Private collection.
- 72 Stefánsdóttir, *Bíbí í Berlín*, 272.
- 73 Ibid.
- 74 ÞÍ. Heilbrigðisstofnunin Blönduósi/Blönduós Health Center, SA/0134.
- 75 Stefánsdóttir, *Bíbí í Berlín*, 359.
- 76 Ibid., 315.
- 77 Þorvaldur Kristinsson. *Þroskaþjálfar á Íslandi: Saga stéttar í hálfu öld*. Reykjavík: Þroskaþjálfafélag Íslands, 2015.
- 78 Ingibjörg Guðmundsdóttir, oral interview with Guðrún Valgerður Stefánsdóttir, 1 June 2021.
- 79 Stefánsdóttir, *Bíbí í Berlín*, 315–316.

## 5 An Independent Person (1974–1990)

### The Basement (1974–1983)

*“Is This Fool Going to Live on Her Own?”*

Upon learning that Ingibjörg Sigurðardóttir – Dear Imba – was assisting Bíbí in her transition out of *Hælið*, numerous residents saw fit to cast doubt upon these arrangements. They posed various questions, such as whether Bíbí could prepare her own meals and manage self-care, and what course of action would be taken if she fell ill. Bíbí considered these inquiries somewhat unfounded, as it was evident that she would naturally be relocated to the infirmary for appropriate care in the event of illness:

I thought this was a foolish question, because if I were to become ill, I would of course have been sent up to the infirmary. ... An old lady who was on the 4th floor overheard our talk and asked, ‘Is that fool going to live on her own?’ I got angry and said, ‘I am not a fool.’ Then the old lady on the 4th floor said, ‘You certainly are a fool.’ Then the woman on the 3rd floor said I was no fool, then she shut up and went on her way.

Then a pivotal day arrived in Bíbí’s life – the day she would move out of *Hælið*. As detailed in her autobiography, Bíbí’s account of her departure from *Hælið* contrasts starkly with her initial arrival. Instead of being a broken and isolated figure, as she had been upon her admission, she was now escaping from the environment that had been her primary residence for almost the past two decades. Bíbí did not embark on this journey toward freedom without reflection:

The old woman who had previously called me a fool, now found it necessary to disrespect my possessions, and called them trash or

junk. I said it was just regular luggage or household things, I had bought a lot of dishes and other stuff used for kitchen work and so on.<sup>1</sup>

Bíbí had diligently prepared for this transition, gathering the necessary items for her new life. As was her customary practice, Ingibjörg had thoughtfully arranged for transportation and enlisted assistance, resulting in a swift and seamless relocation process. Once Bíbí and her possessions had been successfully moved from *Hælið*, she was filled with eager anticipation and promptly set about organizing her belongings in her new abode located in the basement of Aðalgata 7 (Main Street 7) in Blönduós. This significant move took place around October or November of 1974. At this juncture, Bíbí assumed personal responsibility for the first time, at the age of 47 years.

#### *Living an Independent Life: Challenges and Achievements*

During this period, significant shifts in treating people with disabilities were evident in various parts of the Western world, including Iceland. It is likely that Bíbí had no awareness of the emerging societal trends mentioned at the end of the previous chapter, and nor did those responsible for managing services for people with disabilities in Blönduós. The long-prevailing practice of institutionalizing individuals with disabilities, which had persisted for over a century, was rapidly waning, and it may be surmised that the societal changes during this period may have influenced Bíbí's decision to move out of *Hælið*.

In her chapter on moving to her new home, Bíbí refers to herself as “The Mistress of the House at Aðalgata 7.” She elaborates on her initial days primarily arranging dishes and placing books and ornaments on shelves. Bíbí describes how she managed to care for herself, noting that during her time at *Hælið*, she had neither attended to her hygiene nor prepared her meals:

My first lunch was an apple, I did not have anything else on hand, because I did not have a refrigerator, apparently they are very expensive new, and I could not afford to buy one. Ingibjörg had a refrigerator that she had lent her son, but when he bought a refrigerator, he returned it and Ingibjörg lent it to me but only partly. I was loaned half the freezer compartment, but the rest was all mine.<sup>2</sup>

Bíbí occupied a single spacious room in the basement with shared access to a communal bathroom. Initially, she believed she had permission

from Ingibjörg, the homeowner, to make use of a sink in the kitchen located in the basement. However, a young mother and her husband and two sons, who also rented space in the basement, disputed Bíbí's access to the sink. Interaction with this family would become integral to Bíbí's daily life over time.

Despite Bíbí's joy at finally achieving self-sufficiency, she experienced highs and lows during this phase of her life. While she relished her newfound independence and freedom, she grappled with negative attitudes and encounters, particularly taunts and teasing from children in Blönduós. She remarked, "Had it not been for the incessant antics of the local children, I would have felt as though I were in Paradise, in contrast to my time at *Hælið*."<sup>3</sup> The behavior of these children greatly troubled Bíbí, and she attempted to address their actions by reprimanding them and seeking assistance from adult neighbors whenever the children's teasing and harassment became overwhelming:

Eventually kids started coming and misbehaving outside in front of the door and making a noise. I was doing things sometimes and I got fed up with this noise, because I did not think the kids had any business there. Eventually, I chased them off. Then they started playing tricks on me with the window, reaching for the blind and pulling it up if the window was open, or closing the window. And I called them out and told them to leave the window alone; yet they didn't obey much. They, that is the kids, just talked back and told me to shut up and shit in my pants. I told them only old people did that, who were bedbound and couldn't help themselves, or little babies, and that shut them up, this rabble, as I call them.<sup>4</sup>

On numerous occasions, Bíbí mentioned that the police were called due to a group of children throwing trash and snow through her window, breaking windows, and soiling her laundry hanging on the clothesline. Throughout her narrative, Bíbí offered some pertinent advice for parents:

I ask the guardians of the children who were playing tricks on me in the years from 1974 to 1983 to consider the following:

- 1 Would you want to have tricks played on you, or would you like to have your possessions spoilt?
- 2 Would you want dirt put into your baking goods? Housewives should think about this.
- 3 Would you want noise at your windows when you are going to sleep?
- 4 What would you say if someone told you to shut up after you told them off?

- 5 Would you want to be shown the same kind of behavior that was shown to me, that I have described above?
- 6 Would you want snowballs thrown at you when you were ill and wanted peace and quiet, or would you like peace to get on with what you were doing, which was demanding? I needed peace to get on with my tasks, even if they weren't demanding.<sup>5</sup>

Bíbí previously mentioned facing prejudice and taunts from individuals at *Hælið*, but it appears that such experiences persisted during her time on Aðalgata 7. Her account does not indicate that local authorities took significant measures to address the ongoing bullying and harassment perpetrated by children in the community.

### *Cooking on Her Own Terms*

“It was really quite amazing how well I managed to boil food, as I’ve said before I’d seen how it was done, but I thought I’d forgotten, but I hadn’t.”<sup>6</sup> Bíbí alludes here to her constant presence by the stove during her years in Berlín, where she closely observed her mother’s cooking, albeit without active participation. Her culinary experiments did not afford her tranquility from the observant eyes of her daughter:

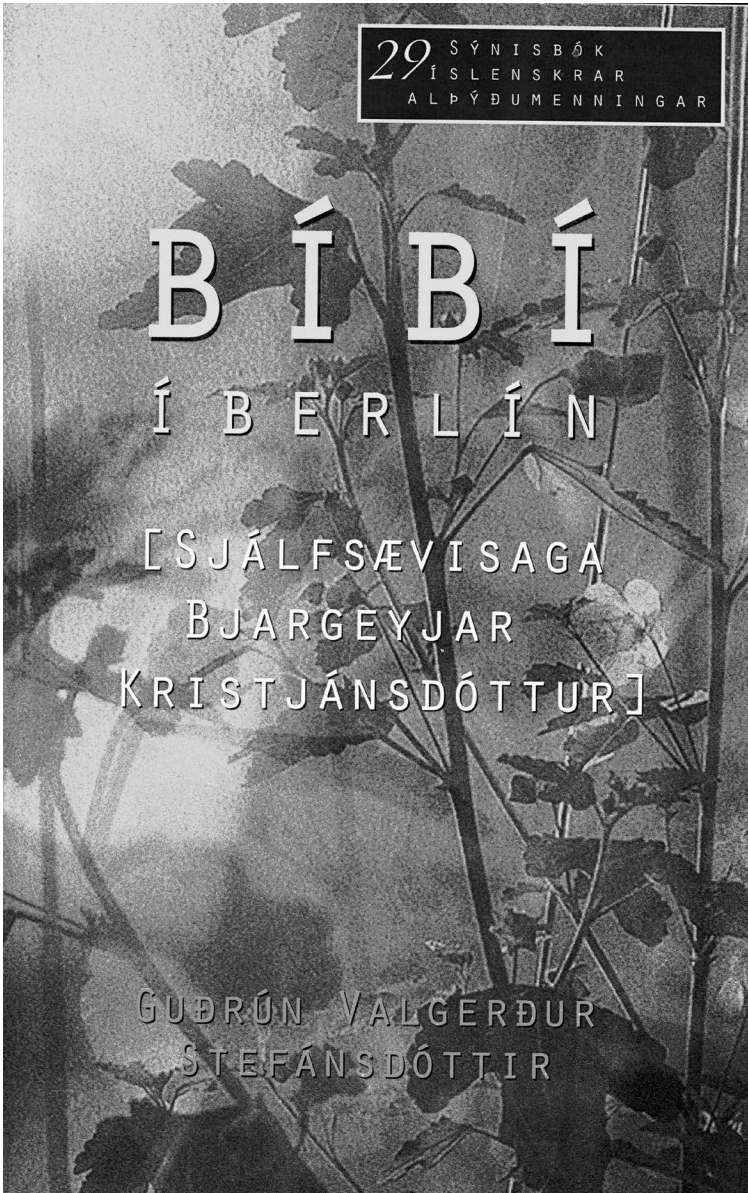
I started trying to bake *lummur* [small pancakes] and even succeeded quite well. I had got a long way with the task. Or had used up some of the ingredients, when a filthy stick was thrown in at the window, it fell on the floor, but I’m sure it was aimed at the vessel that contained the ingredients for the *lummur*.<sup>7</sup>

The sources of Bíbí’s culinary education are discernible. Ingibjörg Guðmundsdóttir, a nurse associated with *Hælið*, gave Bíbí a valuable and practical gift upon her commencement of independent living – a textbook entitled “The Young Girl and Kitchen Work” (*Unga stúlkan og eldhússtörfin*).<sup>8</sup> This textbook of domestic skills enjoyed successive editions in Icelandic elementary schools for several decades. Bíbí intermittently expresses her appreciation for cooking and baking, both for personal satisfaction and for the culinary enjoyment of others, while maintaining her independence from external influences.

Bíbí’s meticulous and prideful adherence to domestic responsibilities becomes evident through her meticulous housekeeping routines, mirroring her mother’s practices from earlier years. She embraced the traditional roles expected of women during her era, encompassing cooking, baking, and maintaining a pristine domestic environment.

Through being a perfect housewife, Bíbí tried her best to become a “normal woman.”<sup>9</sup>





*Figure 5.1* The cover of the published autobiography

*Source:* Photo: Alda Lóa Leifsdóttir.

*Notes:* Bíbí's autobiography was published in 2022 as part of our research project. Bíbí wrote her life story during the years when she had acquired an independent life. Her powerful story is almost unparalleled.

### *Negative Interactions with Neighbors*

Bíbí encountered difficulties with her neighbors in the basement on the first day, as mentioned above. Then her neighbor, who also rented a room in the same basement, refused to accept that Bíbí could use the sink in the kitchen to wash her dishes, so she had to find another way to clean the kitchenware. Bíbí solved this problem by buying a washtub and then fetching water for dishwashing from the bathroom. Bíbí was not happy with her neighbor:

However, it must be said that I found her very odd from the moment I met her. I liked the man better. I did not think he was like her. The boys did not behave as badly when he was at home as when she was home, for it was as if a whole flock of wild beasts had entered the house. They shouted and screamed at each other, and their stuff was like hay scattered all over the place, but I guess it is a modern custom for children nowadays, they aren't forbidden to do anything. I was often afraid I would step on something that slipped out from under me.<sup>10</sup>

It seems that Bíbí's neighbor used her boy against Bíbí. This was also passed on to the "rabble of kids" outside the house. The feud between the neighbor women quickly escalated, but somehow Bíbí could not bring herself to complain about the neighbor to her friend, Dear Imba. She went and complained about the whole group of kids. The older boy from the basement was to be involved again later, in connection with the vandalism of Fagrihvammur, Bíbí's garden:

I could say, and I shall to say, although she [the neighbor] will never read this, that the boy did not know how to play; he just knew how to play tricks on people; that is all he knew, and to be foul-mouthed, that is what I found out later and will tell about it later. That is something else, and I could have told her if I had thought of it.<sup>11</sup>

It is noteworthy that Bíbí consistently harbored the anticipation that her acquaintances would eventually read her autobiographical account, thereby gaining insight into their interactions with her. She refrained from attributing direct blame to the children for their bullying behavior, instead ascribing it to deficiencies in their upbringing by their parents.

### *The Battle of Fagrihvammur*

Over the passage of years, Bíbí increasingly responded assertively to the acts of vandalism within her garden. She started to engage in reasoned

dialogues with those responsible for the damage, permitting herself to express her emotions, and appropriately registered complaints with the relevant authorities:

In the spring of 1986, I noticed two boys approaching from the front when I was transporting soil in a cart down into the garden. I initially paid them no heed until they passed my gate. In an apparent bid to draw attention to themselves, they started pelting rocks at a shed within the garden. I told them they must not do that. However, they persisted and hurled another stone into the shed, and I told them to leave the shed alone, but they threw the third stone, which hit my leg. Enraged, I grasped a plastic shovel to intimidate the boys, but they wasted no time and fled further down the road. I took the shovel to a corner of the fence from where I could observe them at a distance. They started calling me names, and I told them to shut up, that I was going to the cooperative store the next day, and I would ask a lady who worked there to talk to the authorities about how the boys behaved towards me. That was all it took, the boys ran off. I did as I said and told the lady about it the following day, and after that the boys let me alone.<sup>12</sup>

Gradually, Bíbí gained the upper hand in the struggle for control over her garden. As both she and the garden evolved, incidents of vandalism diminished, and a greater sense of tranquility prevailed.

### *The Beautiful Friendship of Anna and Bíbí*

Dear Imba was not the only person who shared a deep friendship with Bíbí. Another loyal friend of Bíbí was Anna Andrésdóttir (1927–1998), a farmwife at Röðull, whom Bíbí affectionately refers to as “the sunshine from the farm Á.” They were the same age and first crossed paths at confirmation classes in Hofsó. Anna was one of four girls to be confirmed; she lived on the farm Á (River) in Unudalur (Una’s Valley), while another girl, referred to as Magga from the farm Enni by Bíbí, was also part of the group. Bíbí’s recollection of her interactions with these girls reveals her varying sentiments toward them: “With Anna from Á and me, we cultivated a profound friendship; she was gentle and amiable, and I found myself more compatible with her than with Magga from Enni, undoubtedly. Anna exuded warmth like a sunlit Sunday, whereas Magga was more like a northerly gale.” Bíbí confides that she concealed her friendship with Anna from her family out of fear of straining familial ties. According to Bíbí, the same secrecy surrounded Anna’s friendship with Alda; her parents and brother disapproved of her forming close bonds with friends.



*Figure 5.2* Bíbí's House, Blönduós

*Source:* Photo: Guðrún Valgerður Stefánsdóttir.

*Notes:* Bíbíarhús (Bíbí's House) at Blöndubýggð 18 in Blönduós. Bíbí lived here from 1983 until she returned to *Hælið* due to failing health, probably in 1993. Photo taken 2020.

It appears that, while she was still living at Berlín, Bíbí maintained some connection with Anna, though this connection waned after Bíbí relocated to Blönduós. Their reunion only occurred when Bíbí fortuitously discovered that Anna was living on the farm Röðull, just outside Blönduós. Subsequently, Bíbí visited Anna regularly, either on foot or with transport provided by Anna. Bíbí paints an affectionate portrait of Anna's family, including her husband and children, as if they were her kin. This underscores the enduring and profound emotional bond between Anna and Bíbí, transcending generations. In the concluding portion of her autobiography, Bíbí describes the dynamic between her two friends:

The fair-haired girl who used to accompany me to Anna Páls in the old days is now 60 years old, both of us old women, being her contemporaries. I refer to Anna Andrésdóttir, who has frequently stood by me through thick and thin, especially recently. Anna often bestows kindness upon me; I sometimes marvel at her gifts of flowers, which I cherish.<sup>13</sup>

This portrayal exemplifies a genuine and enduring friendship. Anna and Bíbí saw themselves as equals, and Anna and her daughters offered Bíbí

unwavering support throughout her life, a testament to the strong nature of their friendship.<sup>14</sup>

### *More Adventures from Aðalgata 7*

Bíbí's descriptions indicate that life on Aðalgata 7 was quite comfortable during the summertime. The friends, Dear Imba, and Bíbí came up with a comfortable routine. They had their Sunday dinners together and traveled around the country on their own and on excursions organized by the Women's Institute. Bíbí also welcomed guests and told the readers of her autobiography that she had welcomed her maternal aunt Jana with a holiday meal of smoked meat and *skyr* (milk curd). After what had passed between them, it must have been a special moment for both of them.

Bíbí enjoyed herself in the garden – Fagrihvammur – in the summer, but in the heavy snow in the winter Bíbí found the basement confining. Snow blocked the windows, and shoveling her way into the open air took much effort:

I had sown the summer flowers some time ago, and they had come up from the seeds and begun to get a little stronger. They were kept in the window during the day, and up on a cupboard at night to start with. Yes, I had to go out beyond the river, which took me quite a while. When I came back and opened the door, I saw a sight that made me very angry. The window had been removed from the hinges – it had been closed when I went outside. Also, snow had been thrown on the floor and on the couch where I slept at night ... Imba was at home when I got home, and I asked her for goodness' sake to ask someone to put the window on the hinges again. I told her that my flowers would die if they were in the cold draft for long. She then went and got someone to put the window back on, and then I went next door and asked a man to report the kids to the authorities.<sup>15</sup>

Bíbí was far from sad when her neighbor in the basement moved out with her husband and sons. The tenants who lived in the basement after them were mostly young single girls. The walls in the basement were thin, and little was unnoticed by Bíbí:

There were many girls that Ingibjörg had rented rooms to, one by one, and they varied in quality. One was named Trippa–Stína. She was usually rude towards me, yet she gave me a potted plant before she went away for good. One was named Lára; she snapped at me once because I was talking to myself, not loudly, I thought she was at work; it was close to noon when it happened. I had to ask her if

she needed to be alone to sleep with boys; I had already seen a boy with her. The third girl also found it necessary to be nasty to me, and it was because of something that I was innocent of. Some of the girls were nice and did not do anything stupid to me, I recognize that. Some of them still had goings-on, with boys, and I will not mention any names, but the poor things had to have some entertainment if you can count it as entertainment. Not all of the boys got in, fortunately.<sup>16</sup>

Here Bíbí refers to an event that happened on the night of 11 December 1977. That night, Bíbí woke up and went to the bathroom. In front of the bathroom was a lad “who was like he was sleeping there; I stepped over him and went my way and did my business, then I went back over the boy and into my room.”<sup>17</sup> In the morning, Bíbí told Ingibjörg and there was quite a scene:

A few days before Christmas, as I was walking outside, I was stopped by a police officer. He was lying in wait for me in a car on the road as I was about to walk by and asked me to answer a few questions. I got into his car and answered readily everything I was asked; it was about this boy who was lying semi-conscious in Imba’s hallway. The following morning, the boy was gone when I went to the bathroom. There was little remarkable about it, except that a boy had tried to get in somewhere else in that house, in another basement at the other end of the house or underneath it, so I heard, but there was no girl for him there.<sup>18</sup>

One may well imagine that it was not always easy for Ingibjörg to have Bíbí in the basement with all these things going on. That same night Ingibjörg became a great-grandmother for the first time. The number of her great-grandchildren rose over the next few years, and the growing family naturally demanded Ingibjörg’s attention. She fell ill in the autumn of 1982 and was sent to Reykjavík for surgery, after which she was admitted to *Hælið* before returning home:

Some time after her return, she got worse, so she had to go up there again, and then she had to be sent to Reykjavík again. The doctors there were amazed; they said that she should have been a lot better, but far from it: after a while, they sent her back home. She was ill after that, and it seemed likely that she would have to be sent back. She vomited often, but before Easter, she was able to vomit up a wad of something, which turned out to be a bit of gauze the doctors had left inside her.<sup>19</sup>

It took Ingibjörg a long time to recover from this medical error. She was keen to be helpful to Bíbí but saw that the conditions in the basement were not ideal for anyone. This resourceful woman once again set out to do something good for her friend Bíbí.

### **Bíbí's House (1983–1990)**

#### *Friends Become Co-Owners*

When Dear Imba was feeling better in the spring of 1983, she bought a small wooden house nearby. Bíbí describes her friend's investment in her own priceless way:

Dear Imba bought it for me and there was a lot of trouble about it, you had to shut up like a clubbed seal, that's how time passed. Around this time or before, Imba comes to me and tells me that Þóra is selling her house and asks me if she shouldn't just buy it for me. Oh, yes, I thought that would be all right. A lot of money was starting to accumulate in the bank account I had, but Imba added more to make up the price.<sup>20</sup>

In many ways, Bíbí was glad to leave the basement. First and foremost, it was because there was always the danger that if Ingibjörg became unable to help her, she would be forced to go back to *Hælið*. On 1 September 1983, Bíbí moved into Bíbí's House. Bíbí describes the house in these words:

Where I live now stands on a patch of meadow and has a flower garden on the south side. Inside the house is made up of six parts: bedroom, living room, kitchen, pantry, boiler room, and upstairs is a small room and storage space. I have been quite comfortable in this house, except this winter, 1989, it's so often been cold, often storms, even gales, but never mind, you could easily store food up in the loft, if it were not for the disadvantage that mice come in there in autumn, and you have to eliminate them with poison, and it wouldn't be good if it got into the food.<sup>21</sup>

For Bíbí, her independence marked a major turning point in her life, and the story shows how proud she was of her being able to stand on her own two feet. Bíbí lived in the house that was named after her until she moved back to *Hælið* due to illness and remained there for a few years until her death. She had a good relationship with her neighbors during the years she lived in Bíbí's House, and she seems to have been subjected to

less taunting there than while living on Aðalgata 7. In her house, BÍbí had privacy to sit, write, and sew in the winter, and she tended to her garden when the weather permitted in summer.

### *Remarkable Self-Defense*

People with disabilities are subjected to more violence than non-disabled people. They suffer equal physical and emotional abuse comparable to other marginalized groups but also makes its members particularly powerless against violence of all kinds. This is especially true for disabled women. British disability scholar Andrea Hollomotz has specialized in research on violence against people with disabilities. She has shown that violence is both greater, more extreme, more socially accepted, and more coherent than against other social groups:

Feminists have put it bluntly: Women are not raped because they are women. They are raped because of men's attitudes, men treating women as property and relationships based on power ... Similarly, disabled people are not violated because they are disabled, but because those who are perceived as different have less power, they are marginalized and targeted.<sup>22</sup>

Icelandic studies reveal comparable evidence. In 2013 a report on violence against disabled women in Iceland was published for the Ministry of Welfare. It is based on interviews with 13 women who had “experiences of multiple forms of violence during childhood and adulthood.”<sup>23</sup> It shows that women with disabilities were much more likely to experience violence than non-disabled women and also to live with long-term violence for much longer periods of time. Also, perpetrators of violence against women with disabilities were significantly more numerous than perpetrators against non-disabled women. The abuse involved parents, support staff, intimate partners, other family members, and government agencies. The report concluded that all the women had experienced childhood violence. Most had been bullied in high school, and five had experienced violence at the hands of husbands or spouses.<sup>24</sup>

As previously mentioned, BÍbí suffered sexual abuse at the hands of her first cousin from Brekka during the Berlín years. It stayed with her forever. She also allowed old Brynjólfur's attempts to kiss her to get on her nerves, for good reason. During the years in BÍbí's House, the following events took place. An “old man” began waylaying BÍbí with the intention to have sex with her. In the beginning, BÍbí was shopping for Christmas, and on her way home, the old man stopped his car and offered her a ride. Instead of driving her straight home, he drove out of town. Nothing is said of what





*Figure 5.3* Bíbí's birthday party: the birthday girl with Ingibjörg Sigurðardóttir (Dear Imba).

*Source:* Photograph from Kristjana Heiðberg Guðmundsdóttir (deceased), loaned by her son Ásgeir Valur Snorrason.

*Notes:* Bíbí with her friend Ingibjörg Sigurðardóttir (“Dear Imba”). They had a close friendship from the time they met at *Hælið* in the early 1970s until Bíbí's death in 1999. Ingibjörg died some years later, in 2003.

took place in the car, but when he turned around and drove Bíbí home the following happened:

When we got home, the man followed me in and wanted to have intercourse with me. He started talking about it and wanted to make me lie down on a couch; I absolutely refused and said I had other things to do. It was before Christmas, and I was going to bake a little; I was pretty surprised at the man acting like this; he was married, and his wife was alive then, when this event took place. I told him his wife would have something to say if she heard anything about his nonsense; he didn't think so. I finally got him to go away.<sup>25</sup>

The old man continued to stalk Bíbí, but she seemed to have had the power, resourcefulness, and ability to handle the harassment. It is almost possible to read from the text that she mocked and ridiculed the man. One time, however, he went further and locked her in a house in a village

some distance from Blönduós to have his way with her, but Bíbí just kept threatening him to tell his wife about his intentions, and he finally yielded and drove her home. This took place in 1988 when Bíbí was in the middle of writing her autobiography.

The last time they argued, the man's wife was dead, but as he had a daughter who lived at Blönduós, it was enough for Bíbí to threaten him to tell his daughter:

You would think a foolish boy about twenty years old might think of acting like that, but not a man who is about eighty. For certain reasons I will not mention the man's name; he has a daughter here in Blönduós, and if she heard about this, she would be angry and would not believe it if she knew who the man was. What I have written is true, even though I did not tell anyone.<sup>26</sup>

Not naming the man indicates that Bíbí made careful judgments about which personal details about other people she was prepared to reveal, and which would remain confidential.

### *Writing for Alda*

In the summer of 1978 Bíbí visited her relatives at Hofsfós. Her father had died three years before; her brother Steini continued to live in Berlín; and her aunt, Margrét, lived at Brekka. On this trip, she visited a woman who had helped Guðrún, Bíbí's mother, from time to time. There was a reunion that had a profound emotional impact on Bíbí. Alda, Bíbí's childhood friend from Þönglaskáli, was there for a visit. They had had no contact since 1945, or for over three decades. However, Bíbí had heard some news about Alda, as she already knew that she had three children, but now she learned that Alda lived in Keflavík, a town in the southwest corner of Iceland, and was married there and had five children:

After this reunion, I wrote to Alda every year, sent her a little treat on her birthday, and made the youngest children happy at the same time. I am going to say that ... it certainly paid off to visit that lady; good deeds often pay off. I was glad I had found the lady and also that I had found a friend there, who I had not seen in years.<sup>27</sup>

The two friends picked up again and remained in a close and good relationship for the next few years until Alda died of cancer in 1989. They were mostly in contact over the telephone, but Bíbí visited Alda in Keflavík almost yearly. What they had in common were their childhood memories, and it is clear that they talked extensively and intimately about past events.

They put them collectively in a new context. It was an emotional journey that led to new interpretations of what Bíbí had experienced in childhood. They were very honest with each other but kept their relationship a secret, especially Bíbí. It was her way of having her friend alone, just for herself.

The annual that Bíbí wrote in 1968 includes a tragic poem about Alda that illustrates how bitter and hurt Bíbí was that their friendship had been torn apart:

I once had a friend  
 In the earlier days in Hofsós, I had high hopes  
 And things went well in the first years  
 But then the wounds started to hurt.

People criticized me to her,  
 But did not look to themselves  
 It does not take long to spoil  
 And to elevate oneself.

I always stood by her.  
 And never let that bond break  
 I do not want to part with any loyalty  
 I cannot cast aside those virtues.

It is best to forget.  
 It happened where I used to live  
 It is best not to talk about it  
 Because probably no one wants to hear.<sup>28</sup>

The two friends had the opportunity to settle the difficult feelings they had both experienced during their childhood and part of that reconciliation found its way into Bíbí's autobiography.

On one of her visits to Alda, Bíbí herself came up with the idea of writing her autobiography, and Alda was thoroughly involved and encouraged her with advice and admiration. It can be assumed that Bíbí read her the chapters as the writing progressed.

Bíbí became part of many diverse communities and had different relationships within them during her lifetime. For example, as reported, she connected to her family very differently from the people who were with her in *Hælið* or the friends she made during her lifetime. Interestingly, it seems that Bíbí kept these social groups largely separate. For example, in conversations with Bíbí's cousins, Kristjana and Áslaug, it emerged that they did not know she had a close relationship with her childhood friend Alda.<sup>29</sup> They were also unaware of the handwritten autobiography, and it

seems that the only people she entrusted with the writing were Alda and her friend, Anna from Röðull. Kristjana explained, for example, that she knew that Bíbí often visited Keflavík when she was in Reykjavík, but not whom she visited.<sup>30</sup> Bíbí never spoke a word to others about her travel to Keflavík. Perhaps this was due to her childhood trauma when her family was trying to keep them apart, or Bíbí wanting to have a private emotional community where she could be herself with Alda, whom she always trusted best.

Alda died before Bíbí's autobiography was complete, at the beginning of 1989. The final chapter of the autobiography describes Bíbí's nostalgia and regret but also gratitude for renewed acquaintance. Bíbí dedicated the book to the memory of her friend Alda Kristín Jóhannsdóttir with gratitude for all the encouragement. At the end of the autobiography, Bíbí evaluates what her legacy will be:

How did it happen that I walked in that direction towards my future garden instead of going somewhere else? And why did I walk farther than usual one day? I can tell you the truth, it was as if I was told to go there. Now, in the summertime, when you go along the road, Svínvetningabraut, far enough to see the farms Sauðanes and Röðull, you can see a small person working in a garden not far from the road. 'Who is this person?' you may ask. Yes, she has made the garden and fenced it in so livestock would not go in and ruin the vegetation. Is this the answer to who the person is? No, it is not. The one who made the garden and the one who wrote the book is the same one. That is the case.<sup>31</sup>

In this short fragment, Bíbí asks who she is, and in her autobiography, she also often wonders what the purpose of her life has been. However, she doubts it can be answered with any certainty. Hence, Bíbí concluded that all the experiences, both good and bad, that she has dealt with in her life story shaped her and made her the person she was. As with most people, Bíbí's identity was multifaceted. It was not just the garden she cultivated with great care, the doll collection she treated with affection, or the collection of her books. Nor did she just carry the labels "idiot," "stupid," or all the slurs she was subjected to during her lifetime, and she was not the little girl sent to the corner of her childhood home behind the stove when guests arrived; Bíbí was something else, something she was searching for her whole life. But it is quite certain that all these factors and many more undoubtedly affected her self-image. Bíbí thus unconsciously reaches similar conclusions to many scholars who define human identity as multifaceted, constantly changing, and being shaped and revised throughout life. In addition, our identity is shaped through interactions and social

relationships with other people, and groups we associate with and are a part of, during our lifetime.<sup>32</sup>

Bíbí does not mention her health problems in the final chapters of her autobiography. At the end of the book he leaves the reader as she sits in Bibí's House, surrounded by her dolls and even on the way up to Fagrihvammur. She has consciously decided to put a happy ending to her story. Bibí's medical records show, on the other hand, that in the last few years her health had begun to fail. Nevertheless, the author felt that those medical stories had no place in her book.

### From the Autobiography – *Bíbí in Berlín*

#### *Bíbí Lets Herself Dream*

*I have thought often about it, maybe not out loud, but what shall I say, I often feel sad about never having had a normal child myself, but still, I do not envy those who enjoy that good fortune. I would have taken good care of it and taught it good manners and made it obedient, but that would not have been possible unless I had been normal, then I would have left home when I was 14 to 15 years old. Then I would have earned money, enough so that I could have learned what I was interested in, maybe I would have learned gardening and sewing. I would have sewn for others if this had happened, and done gardening, if I had been normal and married a man who had become rich, but I would not have charged for the sewing if that had happened, but it would never have occurred to me not to have something to do, besides the household chores. I wouldn't have minded having eight children with him, I would have trained them to obey me unconditionally. Maybe I would have got hold of a man and set up home and run a large farm in the countryside. Then I wouldn't have been like some people, traveling to other countries, except maybe twice, because otherwise, I wouldn't have been able to help others, as it takes a lot of money to be able to do so. Then maybe I would have learned to drive a car, so I could go wherever I wanted, to visit my friend at the farm Röðull, among other places. I could also have ridden Skjóni, my horse, and visited people in the countryside. What would the people at the farm Brekka have said then, had that happened? Or the other relatives? They would not have believed it until they saw it for themselves.*<sup>33</sup>

#### Notes

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- 2 Ibid.
- 3 Ibid., 316.
- 4 Ibid., 284.
- 5 Ibid., 287.

- 6 Ibid., 280.
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- 8 Ingibjörg Guðmundsdóttir oral interview with Guðrún Valgerður Stefánsdóttir, 1 June 2021.
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- 11 Ibid., 282.
- 12 Ibid., 304.
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- 18 Ibid.
- 19 Ibid., 341.
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- 21 Ibid., 354.
- 22 Andrea Hollomotz, “Disability, Oppression and Violence: Toward a Sociological Explanation,” *Sociology* 47:3 (2013): 478.
- 23 Ásdís Aðalbjörg Arnalds, Hrafnhildur Snæfríðar-og Gunnarsdóttir, *Ofbeldi gegn fötluðum konum. Skýrsla unnin fyrir Velferðaráðuneytið*. Reykjavík: Velferðaráðuneytið/Ministry of Welfare, 2013. [https://www.velferðarraduneyti.is/media/velferðarraduneyti-media/media/Rit\\_2013/ofb\\_fatladar-konur-skyrsla\\_mai2013.pdf](https://www.velferðarraduneyti.is/media/velferðarraduneyti-media/media/Rit_2013/ofb_fatladar-konur-skyrsla_mai2013.pdf), 3.
- 24 Ásdís Aðalbjörg Arnalds, Hrafnhildur Snæfríðar-og Gunnarsdóttir, *Ofbeldi gegn fötluðum konum*, 5–6.
- 25 Stefánsdóttir, *Bíbí í Berlín*, 343–344.
- 26 Ibid., 344.
- 27 Ibid., 290–291.
- 28 Ég átti einu sinni vinkonu/ Í fyrri daga á Hofsóss og var mjög að vonum/ Og það fór vel fyrstu árin/ En svo fóru að sviða sárin. Það var farið að finna að henni við mig/ En athugað ekki sjálft sig/ Það þarf ekki langan tíma að spilla/ Og sjálft sig eitthvað að hylla. Ég hélt alltaf með henni/ Og aldrei því niður renni/ Ég vil ekki slíta við neinn tryggðum/ Ég get ekki frá kastað þeim dyggðum. Það er best því að gleyma/ Það gerðist þar sem áður átti ég heima/ Það er best að tala ekki um það/ Því að líklega vill enginn það heyra. *Annal of Bjarney Kristjánsdóttir (Bíbí) – manuscript – Poetry*. Private collection.
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# 6 From Hofsós to the Other World

## An Afterlife Story

### Bíbí in Her Element

After the autobiography *Bíbí in Berlin* was published in Iceland in the spring of 2022 it immediately attracted great attention, *inter alia* from Bíbí's relatives and people who had known her and were part of her community. Before the autobiography was published it had also been the subject of some discussion, after it received media attention. In this chapter we are going to identify the characteristics of the discourse that took place, using the methodology of historical discourse analysis.<sup>1</sup> The focus will be on the following questions:

- 1 What is it that characterizes the discourse about Bíbí?
- 2 What common threads are found in this discourse, and what contradictions?
- 3 The research also posed the question of how far this communication reflects how ableism and microaggression can be detected within the discourse.

Ableism is not simply a question of ignorance or negative attitudes towards disabled people, it is also an unrealistic aim of perfection and a deeply ingrained way of thinking about bodies. It feeds the idea that disability is negative and undesirable.<sup>2</sup> Microaggression is one manifestation of ableism; the term is used to describe harassment such as recurrent negative behavior and insinuations experienced by disabled people in their daily lives. Microaggression often appears insignificant, but it can have a grave impact on a person's mental well-being to be subjected to such aggression repeatedly, and many times a day. This is a form of hidden abuse, whose victims tend to be members of marginalized social groups.<sup>3</sup> Bíbí's autobiography shows that she was subjected to a great deal of microaggression in her daily life; in this chapter the manifestations of microaggression are explored in the discourse that arose about Bíbí before and after the publication of her autobiography.

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## The Background

After work had commenced on Bíbí's autobiography, i.e., before it was published, a number of presentations took place regarding Bíbí and her life, *inter alia* at conferences held at the University of Iceland. Bíbí immediately attracted attention, and that gave rise to considerable coverage of the autobiography even before it was published.

The author, Guðrún Valgerður Stefánsdóttir, gave the first public presentation on Bíbí in the spring of 2018 as part of *Pjóðarspekillinn*, the annual Social Sciences Conference at the University of Iceland. After the conference an interview with her was published in the daily *Morgunblaðið*. Following this, great interest in Bíbí emerged, and Guðrún received phone calls and emails (see summary below). The people who got in touch were individuals who remembered Bíbí during her time living in Hofsó's (her childhood years) and in Blönduós, as well as close relatives in Reykjavík. Most of them had stories to tell about Bíbí, and they also passed on details of others who had known Bíbí, and family members, and this was of great value in the ongoing research. These leads were followed up, and many individuals were interviewed. One of the phone calls was from a close relative, who features in the autobiography. She was an elderly lady, and she died some months after the conversation. She was one of two people named in Bíbí's medical records as her next of kin, and she had had a relationship with Bíbí and her family from childhood.<sup>4</sup> Hence, she knew Bíbí's story and her family better than most of the others who made contact with us, and she had a lot to say about the life of Bíbí and her family. She also referred us to other relatives who she thought might be able to provide information on Bíbí's life, and they were subsequently contacted.<sup>5</sup> At the start of the conversation she expressed curiosity about what the autobiography might say about her and other relatives. She was worried about what Bíbí had written about them in her autobiography, pointing out that Bíbí had not always had a favorable attitude toward her relatives, and that on occasion she could snap at them and be unfair. Like others who made contact, she was surprised that Bíbí had written the autobiography. She had not known of her writings.

This initial response was interesting and encouraging; it emboldened us and spurred us on to continue our work with the autobiography. After the coverage of Bíbí in the media and elsewhere, considerable discussion of her took place on the Facebook page *Brottflyttir Blönduósingar* ("Former Blönduós residents"). The name is a little misleading, as the group includes both former and present residents of the town.

Shortly before publication of the autobiography, the research team gave a presentation at a seminar at the University of Iceland Humanities Conference in the spring of 2022. Attendance was good, and after the



presentation questions were invited. It transpired that a large number of former Blönduós residents who remembered Bíbí were in the audience. The seminar had been advertised on the above-mentioned Facebook page for former Blönduós residents. A lively debate ensued about Bíbí, and various information emerged, which provided the basis of discussion in this chapter. As in the case of Bíbí's relative mentioned earlier, many who spoke were interested in finding out what Bíbí had written about Blönduós folk in her autobiography. An elderly man who remembered her asked with a smile: "I suppose she just spoke unfavorably about Skagafjörður folk?" A traditional rivalry exists between the residents of the two neighboring counties, Skagafjörður where Hofsó is situated, and Húnavatnssýsla where Blönduós is located. In other words, people were concerned about what Bíbí might have written about them personally, and about people in Blönduós in general.

At one of the seminars held about Bíbí the question also came up of the cause of Bíbí's disability. A man in the auditorium then stood up and introduced himself as Bíbí's physician for many years. He confirmed what



*Figure 6.1* Bíbí and her dolls

*Source:* Photographs from sisters Lilja and Sesselía Hauksdóttir.

*Notes:* This remarkable photo of Bíbí with her dolls is probably considerably more recent than the picture of her with some of her dolls, seen earlier. Initially she was made to feel embarrassed about her doll collection, but when she looks back at the end of her autobiography, she clearly takes pride in the collection. She saw her dolls as sentient beings, and she explains that they took the place of the children she never had.

had been believed, that Bíbí had been born with a congenital thyroid disorder and that she had not received appropriate medication until 1976. He added that her health had improved once she was medicated, and that she had more energy. This was before we had gained access to Bíbí's medical records at the National Archives of Iceland, discussed above, which confirmed the diagnosis. After the seminar he wrote the following on the *Brottfluttir Blönduósingar* Facebook page:

The seminar was informative and enjoyable. It was well attended, and a good group of former Blönduós people was present. Bíbí's autobiography will be published in the coming weeks. An extraordinary achievement by this remarkable woman. I look forward to reading the book.<sup>6</sup>

Considerable anticipation and interest in Bíbí's autobiography had thus arisen before publication, and many people waited avidly for the book.

Great interest and debate were sparked by an interview with the author, shortly after publication, on *Kiljan*, a popular cultural show on RÚV national TV. The interview came about after Davíð Ólafsson, one of the editors of *Sýnisbók íslenskrar alþýðumeningar* (Anthology of Icelandic Popular Culture) was sitting in a local café when the host of *Kiljan*, Egill Helgason, entered the place. Davíð accosted him and tried to persuade him to include Bíbí's autobiography in the TV show. Egill doubted that he would have space for it, as the show's season was coming to an end. Not all Icelandic books are featured on the program; in fact, just a very few of them are discussed on the show. In the small café was another person, who heard their conversation and approached them. He said he had just finished reading the autobiography, and he was speechless – he asserted it was simply brilliant! Egill was unsure what to think, but in the end, he invited Guðrún Valgerður to appear on *Kiljan*, where he took a long and substantial interview and discussed the book in great detail. He was obviously very impressed with Bíbí and the book and this came out clearly in his presentation. After it was broadcast there was a strong response from the public: both from Bíbí's relatives and people who had known her in Blönduós and Hofsó's, and also regular viewers of the show who were struck by Bíbí's very unusual life story. The reaction was indeed strong – Bíbí became the talk of the town!

### Historical Discourse Analysis

French historical philosopher Michel Foucault sees discourse as a force that constructs meaning in society, that is characterized by being always upheld by a power that generally lies beneath the surface and is thus hard

to recognize.<sup>7</sup> He also points out that logical context is always culturally defined, and thus the discourse must be subject to the influences and influencers that are dominant at each time, and hence to those who hold power. Social groups thus determine the discourse that takes place within it, deciding what is true and untrue. All discourse is also marked by trends and movements, theories and scientific knowledge at any time, and determines who is important enough to be the guardian of truth. The discourse is furthermore demarcated by who has the right, and hence the competence, to make use of it.

Public discourse regarding disabled people, and not least those with intellectual disabilities, has since the late 19th century reflected the great influence of genetics and medical science, which have played an important role ever since in shaping attitudes toward this social group.<sup>8</sup> In culture and historical discourse such individuals are commonly likened to children or invalids, or even animals, and a danger to the “race.” It is even alleged that they have uncontrollable sexual urges and a violent nature.<sup>9</sup> In contrast with such stereotypes, disabled people have sometimes been presented as heroes or “super crips” who have overcome their disabilities, if they achieve something unexpected.<sup>10</sup>

By examining the discourse, power relations may be revealed, and how attitudes to certain marginalized groups have evolved and come to be received wisdom, which in Foucault’s view can give rise to exclusion and marginalization.<sup>11</sup> Anything that does not conform to prevailing standards is deemed “abnormal” and undesirable. Such discrimination can prove especially harmful to marginalized groups, who have rarely had the opportunity to speak out against power. On the other hand, in Foucault’s view power of all kinds can spark opposition to received ideas: for example, protest and criticism from disabled people regarding socially structured barriers, and not least against negative attitudes and discourse vis-à-vis disabled people. The objective of discourse analysis is to reveal diverse manifestations and contradictions in the discourse. The contradictions are thus part of the discourse, and through them, it is often possible to discern opposition to dominant elements of the culture at any time.<sup>12</sup>

### **Reception Groups**

Participants in the discourse about Bíbí may be divided into several categories: firstly, her close relatives in Hofsós and Reykjavík. Secondly, people in Hofsós who had known, or remembered, Bíbí. Thirdly, former and present residents of Blönduós. Finally, people who had not known Bíbí but became interested in her life story after the autobiography was published. In addition, university experts in Humanities and Social Sciences, especially in History, Disability Studies, and in the field of disabled people,

gave the book a lot of attention. Not at least because there are few sources like Bíbí's story, that shed such a clear light on the development of 20th-century society and the history of marginalized groups.

Some of these people had known Bíbí well, others were acquainted with her, while yet another group had only seen her out and about or knew her by reputation. Some of the women had become friends of Bíbí. The Blönduós group included people who had worked at *Hælið* and had got to know Bíbí there. Some had known Bíbí as an adult, others as children. Clearly, the discourse of the groups differed, reflecting the variable relationships between Bíbí and the people in the reception groups, and the fact that these individuals had known Bíbí at different stages of her life. It needs to be kept in mind that part of the research period coincided with the COVID-19 epidemic, so some of the contacts had to take place by phone or the internet.

The discourse analysis that follows is based on data gathered through the reception groups; in addition, personal conversations and phone calls took place with people from Blönduós and Hofsós, and relatives in Reykjavík as well as with general readers of the book. The data and their extent will be presented below:

Most of the individual interviews/conversations were recorded and transcribed verbatim, while detailed notes were made of telephone interviews, the public meeting in Blönduós, private visits with relatives in Hofsós, and the above-mentioned conferences. The data were then analyzed using the methods of historical discourse analysis and placed in the context of ableism and microaggression.

Foucault points out that discourse entails a process of constant creation and re-creation and that in the discourse discursive themes appear repeatedly in the texts studied. In an analysis of the data, we sought discursive

Table 6.1 Summary of Research Material.

<i>Summary of Research Material</i>	<i>Extent</i>
Phone calls and emails received after media coverage of Bíbí	10
Conversations/interviews with relatives and others who had known Bíbí in Hofsós, including three phone interviews	6
Conversations/interviews with older Blönduós people who had known Bíbí, including two phone interviews	5
Public meeting in Blönduós about the book and Bíbí's life, 30 May 2022	35
Facebook page for former and present Blönduós residents	20
Public discourse: blogs and responses to coverage and interviews with the authors in the media	6
Notes made after seminars at conferences: <i>Þjóðarspejillinn</i> (Social Sciences Conference), <i>Söguþing</i> (Historical Convention), <i>Menntakvika</i> (Educational Conference)	3

Table 6.2 Discourse Analysis.

<i>Principal Themes</i>	<i>Discursive Themes</i>
Untruth and ingratitude Hero	Lies, ingratitude, gratitude, pushiness, eccentricity, entitlement, anger, underestimation, doubts, and difficult Surprise, praise, autobiography, garden, recognition, and survived
Victim	Pity, sympathy, helpfulness, empathy, condescension, and goodwill
Respect - affection	Garden, autobiography, good, helpful, sympathy, human being, credible, pride, friend, generous, good with children, good company, and affection
Underestimation	Doll collection, library, physical features, defense, fear, shunning, observant, ableism, and microaggression
From the other world	Affection, sympathy, recognition, psychic, faith/skepticism, and good

themes which formed a pattern in the discourse and explored whether they could be viewed as historical or political legitimating principles.<sup>13</sup> From the themes of the discourse, we identified principal themes, and whether contradictions were to be found in the discourse. In the discourse analysis, repeated discursive themes give rise to several principal themes or categories of discourse:

On the basis of these word categories and discursive themes various obvious contradictions were revealed in the discourse. Bíbí was, for instance, characterized both as a hero and a victim; she was underestimated, yet also shown respect; some people were afraid of her, while others were fond of her. The last category, *From the other world*, stands out from the discourse and comes as a surprise – not least because it is probably unusual to receive a message from beyond, and it puts the recipient in an awkward position. The options were either to omit this part or to try to describe the message and the background, as is done here, without taking any position on belief in an afterlife.

### **Untruth and Ingratitude – The Discourse in Hofsós**

Bíbí's relatives from Hofsós expressed a keen interest in her autobiography when they learned that it was to be published. Views changed considerably, however, and interest dwindled after those people had read the book. This may be due to the fact that in the autobiography Bíbí spared neither her relatives nor the people of Hofsós; she made fun of some, ridiculed others, and told tales about them. This applies particularly to those whom she perceived as having slighted her or those she disliked. She also wrote about various embarrassing events that were uncomfortable for some, about

which there had been a conspiracy of silence. The fact was that Bíbí listened and noticed what was said; people appeared not to have been aware of her powers of observation. Thus various facts found their way into her autobiography which people had probably not expected to read there.

Some of Bíbí's Hofsó's relatives were surprised that she had been able to write, and nothing could challenge their opinion. The predominant theme of the discourse was, on the other hand, considerable doubt about her competence to give a true account of people and events. Such views were backed by arguments that "she didn't really have the wits to know right from wrong," as one distant relative put it. A further argument in support of that view was put forward by Bíbí's close relative: "There were travelling booksellers inducing her to buy books and all sorts of junk which was of no use to her, and Bíbí bought collected editions of some authors' writings that she never took out of the shrink-wrap." Here, doubt is cast on Bíbí's cognitive skills, and she is represented as simple and easily fooled while belittling her interest in books.

As stated above, from an early age Bíbí was keenly interested in books and reading. She read a lot and soon acquired her own collection of books. She also reports that over the years she often had to prove that she could read and write; she felt that her library was proof of that fact and that it gained her more respect. That was not enough, however. As stated above, efforts were made to demonstrate that there was little point in collecting books if one had no the mental powers or skills to understand them. We gained access to her library, as previously stated; none of the books was still in the shrink-wrap. On the contrary, many of the volumes appeared to have been read repeatedly by Bíbí.

Among the events recounted by Bíbí in her autobiography is sexual abuse at a young age by a male relative, who is now deceased. One of Bíbí's Hofsó's relations remarked of the man concerned: "He was a good lad. He'd never have hurt Bíbí – he was probably just teasing her, getting up to some childish mischief." But Bíbí's account is convincing and is consistent with many women's experiences of sexual abuse and harassment. A particularly typical aspect of the reaction to the abuse is the conspiracy of silence around sexual abuse. The family member is unwilling to believe in the relative's guilt and belittles Bíbí's story. As has been pointed out, those who hold power, and groups in society, determine which individuals are regarded as worthy to be keepers of the truth.<sup>14</sup> To the family member, the truth is obvious, yet this example clearly demonstrates the imbalance of power between the woman with a disability and the able-bodied young man.

In her autobiography Bíbí tells stories of various potentially embarrassing events in her home district when she was growing up: for instance, cases of children being wrongly fathered. She writes particularly about one such case involving a relative of hers, which has been discussed above. An

elderly man who remembered Bíbí well and was well informed about Hofsó's history, welcomed the publication of the book. He commented: "Bíbí lances certain boils. Some of what Bíbí related is known to all, such as wrong paternity, and even her father's violence, which has never been spoken about." Here we see an example that contradicts the above example of the response to Bíbí's sexual abuse: this man regards Bíbí as credible, and essentially corroborates her account. Bíbí's stories in her autobiography thus challenge the conspiracy of silence and what lies beneath the surface, and that appears to have been an uncomfortable experience for some of Bíbí's relatives and former neighbors.

Another close relative of Bíbí indicates that she had been ungrateful to her relatives in Hofsó's, who had been doing their best, treating her kindly and feeling sympathy for her. Bíbí had, for instance, been invited to stay for a while at Brekka with her cousin in Hofsó's. Bíbí accepted the invitation once or twice but had then been "nothing but demands and ingratitude," as a relative put it. Bíbí was picky about her food and complained that the children in the family were too noisy. Historically, attitudes toward people with intellectual disabilities reflect *inter alia* the assumption that they are dependent on the kindness and goodwill of others and that they should be grateful for what they get.<sup>15</sup> It is not unlikely that such attitudes unconsciously colored Bíbí's relatives' perception of her ingratitude, and that they expected more gratitude from her.

An elderly lady who was a friend of Bíbí's mother said much the same as Bíbí's relatives. She said she had known Bíbí well, that Bíbí had often visited her with her mother; it was safe to say that Bíbí did not have the wit to give a true account of certain events, she asserted. "Bíbí was retarded, of course, that was obvious. She was often unfair and ungrateful to her mother and to her brother Steini, who was never unkind to her as she says in the book. That was just a lie." In this context the question may be asked again: who are the guardians of truth? As in the example above, the veracity of Bíbí's account is placed in doubt, and that is attributed to her disability. This is a typical element of cognitive ableism.<sup>16</sup>

Others also recounted that Bíbí had often been angry and unfair in her behavior towards her family and relatives. It is scarcely possible to imagine the microaggressions Bíbí must have experienced, which are indicated by her relatives' attitudes toward her, expressed above. One aspect of microaggression is when the community is constantly informing the person, directly or indirectly, that they are a heavy burden, and disregards their opinions or narratives.<sup>17</sup>

Despite the negative reactions, and despite the way that some people have belittled Bíbí and her abilities, there were also favorable reactions to the book in Hofsó's. A close relative of Bíbí talked about her with affection and respect; she said that she and Bíbí had had a good relationship when she was a little girl. She found Bíbí fun and was pleased when she came

visiting and was also impressed by Bíbí's doll collection; she was one of the chosen few who were allowed to play with the dolls.

Hofsós people we spoke to also felt that through her autobiography Bíbí had raised the profile of the village of Hofsós and its environs, and to some extent brought credit to the place. Those who expressed such views had not known Bíbí personally, as they were considerably younger than she. The book was read, for instance, with great interest in the Hofsós primary/lower secondary school, where it was read aloud during recess. A teacher at the school whom we met by chance in the village described Bíbí's accounts of the past, social life, animals, landscape, and beauty of Skagafjörður as of great value, and conducive to awakening the pupils' interest in their surroundings – as well as for tourists who visit Hofsós.

### **Hero or Victim? – The Discourse in Blönduós**

Shortly after the publication of the autobiography the research team held a public meeting in Blönduós which was attended by about 35 people, most of them Blönduós residents who had known Bíbí or remembered her. On that same visit the team visited *Hælið* in Blönduós, where Bíbí lived in the geriatric department for 17 years. We were treated to coffee and cakes, and we met two elderly ladies who had worked in the geriatric department for some of Bíbí's time there. They had clear memories of Bíbí and told us stories about her life in *Hælið*. The events recounted here, and others, make up part of the data for this chapter.

Blönduós people, like those in Hofsós, were surprised to discover Bíbí's ability to write her autobiography and her good command of the Icelandic language. The discourse was, however, generally far more favorable in Blönduós than among Bíbí's Hofsós relatives and friends; and on the Facebook page for present and former Blönduós residents lively debate took place about Bíbí and her book. On the Facebook page shortly after the book was published, remarks included: "you see an entirely new side to the woman," "remarkable, quite remarkable," and "although I knew her for a long time, this would never have occurred to me."<sup>18</sup>

As witness these remarks, Bíbí's autobiography came as a great surprise to Blönduós people, many of whom had thought, like her relatives in Hofsó's, that she could neither read nor write. The discourse on the Facebook page is exemplified in the following entry:

I'm just getting to the end of this extraordinary book. I remember Bíbí well ... I recall that when I asked, as a youngster from the country, who this woman was, I got the answer: "Oh, that's just Bíbí." I think a lot of people of my age took that as a valid answer ... and didn't expect any "mental accomplishments" such as her story-writing, which I think is amazing and really an astonishing achievement, in light of the circumstances of her early life!<sup>19</sup>



The question may be asked, why no “mental accomplishments” were expected of Bíbí, and the answer was stated in the remarks of one person who spoke at the public meeting in Blönduós: “it was simply assumed that she was retarded.” This discourse, like that of Bíbí’s Hofsós relatives, may be defined as cognitive ableism: the predominant attitude in the community was the assumption that Bíbí did not have competence similar to that of people without disabilities, due to her intellectual disability.<sup>20</sup> Bíbí’s book thus shook up the discourse, challenging its legitimizing assumption that people with intellectual disabilities cannot do the same things, or comparable ones, as those without disabilities.

That aspect of the discourse in Blönduós was, however, characterized by a positive attitude towards Bíbí and recognition of her talents. No doubt was cast on the veracity of her stories – unlike the discourse of some of her relatives in Hofsós. Many stated that they realized that Bíbí had been misunderstood and that she had not received the treatment and respect she deserved.

In an open blog entry, Þorsteinn H. Gunnarsson described Bíbí as a hero, who survived appalling conditions, and other people expressed similar views.<sup>21</sup> And one may certainly agree that Bíbí was a remarkable person who found her own ways of dealing with a difficult life and social exclusion. It has, however, been pointed out that one of the stereotypes of disabled people is to frame them in the role of hero or savant, overcoming their disabilities and achieving something not expected of them.<sup>22</sup> The discourse on Bíbí reflected such stereotypes to some extent, as seen above. Due to the autobiography, people may thus have regarded Bíbí as having in a sense overcome her intellectual disability and achieved a remarkable outcome, thus rising to the same level as people without disabilities.

In contradiction to the “hero” discourse, another one of fear also emerged; stories were told of people, especially children, having been afraid of Bíbí, not least due to her appearance. One person remarked: “Maybe people were afraid of her because of her expression, and she often dressed oddly, differently from other people. She was tiny, and always carried a stick or cane that she leaned on.” The discourse also suggested that Bíbí’s isolation had been of her own making and that she had shown little interest in interaction with others. One woman at the public meeting in Blönduós said: “I always said *good day* to her, but she didn’t always respond – sometimes she would just mumble something to herself.” Another said: “She didn’t talk much, naturally enough, as people didn’t speak to her much.”

Ableism engenders the idea that disability is essentially negative.<sup>23</sup> It has been pointed out that the non-disabled gaze embodies ableism, as the gaze of the non-disabled majority, is perceived as the norm. As seen above, the discourse focused on Bíbí not being “normal,” and blaming her and her physical appearance, rather than the obstacles posed by the

community's negative attitude to Bíbí. Thus Bíbí was not expected to be a participant in the conventional conversation, i.e. people did not speak to her, and this is a clear example of microaggression, especially where recurrent exclusion takes place, as in Bíbí's case; this becomes a theme in interaction. Disabled people have made the point that the non-disabled gaze obstructs participation in the community by disabled people due to the constant, often negative attention they attract; they do not conform to the norm, and hence they disrupt the "social stability" of their surroundings.<sup>24</sup> So it is not surprising that Bíbí avoided talking to people or wishing them a *good day*, as she was accustomed to being targeted by teasing, harassment or negative attention, or even being ignored, as recounted above.

Though indications are that Bíbí was not much listened to, it was maintained both on the Blönduós Facebook page and at the public meeting there that she had been contented in Blönduós; that most people had treated her well, especially in her later years. At the public meeting one Blönduós resident observed: "She was only teased by about two or three lads. It wasn't everyone." But not all agreed, and one woman said: "It's damned nonsense that she wasn't teased, and we should simply admit it. That's the way it was, and Bíbí was often treated unkindly here in Blönduós." If this talk is viewed in the context of microaggression, it is clear that Bíbí was subjected to constant harassment, teasing, and sometimes abuse and that is consistent with her own account in her autobiography.

On the Facebook page for former and present Blönduós residents, a number of women who had worked at the retirement home where Bíbí had lived spoke about her after the book was published. All stated that they had been fond of Bíbí, and showed respect for her and understanding of her situation. This affectionate account is a good example of the views of many who had worked at the home about Bíbí:

I got to know Bíbí well when I worked at *Hælið* in the old days. We were friends and she confided in me about various things that were confidential between us. She told me she had been belittled in her youth, and among other things she believed she was short because of that, and she had various things in her keeping that proved that she wasn't what people thought ... I'm so pleased that her story has been published in book form. God bless the memory of my dear Bíbí.<sup>25</sup>

Many Blönduós people recounted that they had felt sorry for Bíbí, sympathized with her, and been kind to her, inviting her to their homes for coffee and meals, and assisting her in various ways. One former employee at the home said in a personal interview: "She was somehow so alone, I

felt sorry for her and tried to be good to her, and I think many others did so too.” In conversation with another woman who had worked at the home, the following was said: “It’s an awful fate for a young person to live in an old people’s home, and I think that many of us young women who worked there tried to be kind to her, and give her this and that, and Bíbí appreciated it.”

It is certainly true that it was an awful fate for a young woman to have to live at a retirement home. But the question may be considered, when goodwill and empathy cross over into “patronization” or condescension, which is one manifestation of microaggression towards disabled people. This is seen in the widespread perception that people with intellectual disabilities are like children who never grow up, and victims, dependent upon others; and that is how they are often treated. Pity is one of the corollaries of patronization; disabled people have themselves stated that pity often characterizes the way that people without disabilities behave towards them. Disabled people are also, they say, perceived as helpless, and people without disabilities are constantly offering assistance, and even “helping” when the person has declined.<sup>26</sup>

It should be stated, however, that it emerges clearly in Bíbí’s autobiography that she appreciated being shown understanding and empathy. She writes about people who were good to her, no less than about the others who offended her, or whom she disliked. It is not unlikely that Bíbí experienced empathy, pity, and patronization.

In contradiction to the discourse of fear described above, stating that children especially had been afraid of Bíbí, several women who had known her well as little girls recalled that she had been kind to children, and had been good to them. All of them had often visited *Hælið*, either because their parents worked there, or they had themselves been admitted to the hospital wing as children. The characteristic feature of these childhood narratives was affection for Bíbí. The dolls were a whole world of wonders, and the implication of these entries is that, even though some of the girls had found Bíbí odd, she was more fun than most other people in their view. One of them had been hospitalized at *Hælið* for some weeks; after she was discharged, she was allowed to visit Bíbí, who welcomed her. She reported that her interaction with Bíbí had made her time in the hospital easier and helped her pass the time. She often visited Bíbí after she returned to normal life.<sup>27</sup>

A good friend of Bíbí from Blönduós, who was her contemporary, said the following in a personal interview:

Bíbí was just a person like the rest of us, though she was unusual, of course. She was a good woman, and that was seen in her behavior towards my mother. She was also great fun and told entertaining



Figure 6.2 BÍbí's designs

Source: From BÍbí's diary Photo: Sólveig Ólafsdóttir.

Notes: BÍbí made outfits for all her dolls, clearly taking great pains with finding the right designs and fabrics for each one. Drawings by BÍbí.

stories of events and people at the retirement home and in the town. We laughed together a lot. She visited me every Saturday morning for a long time and had cocoa and biscuits that Bíbí liked. Over time we became good friends.

She recounted that Bíbí had been good to her elderly mother; the two women were together at the retirement home for some time. Her mother's condition declined and she was transferred to the hospital wing, where she remained until her death. According to her, Bíbí's visits were greatly appreciated by her mother, in the monotony of the hospital wing. Unlike the victim/pity discourse, she describes an equal friendship with Bíbí and states that it was important to Bíbí to reciprocate the kindness of those who had been good to her, such as her mother. Her mother is featured in Bíbí's autobiography: Bíbí's account and hers are consistent.

A woman who worked at the Cooperative store in Blönduós for 30 years states that Bíbí was a frequent visitor there. She reports providing Bíbí with various items for her dolls, such as small shoes that had not sold, yarn for knitting dolls' clothes, and fabric for sewing. She said that many other women who worked in the shop had done the same for Bíbí. She would often come into the shop and sit on a stool near the staff. "They were fond of Bíbí and enjoyed chatting with her," she said. This example and others indicate that Bíbí enjoyed goodwill and affection from many in Blönduós and bonded with people there. The discourse also shows that attitudes toward Bíbí changed over time, as stated in this entry: "Bíbí certainly made her mark on our town, and people came to appreciate her in time."

### **Respect and Underestimation**

In time Bíbí's garden at Fagríhvammur gained great admiration and respect in Blönduós, although her gardening was probably deemed odd initially, and a sign of her eccentricity and weirdness. Probably few believed that it could ever develop into a beautiful garden. Many Blönduós people remember Bíbí walking back and forth every day (about 4–5 km each way) from *Hælið*, where she was still living when she started gardening, and later from the center of Blönduós where she lived for the latter part of her life. At the public meeting in Blönduós, for instance, an elderly man said: "I remember her carrying buckets and plants and so on to the garden, all that way. Of course, she was an odd sight, but one could only admire her diligence."

The discourse about Bíbí's gardening was in many ways reminiscent of the "hero" discourse discussed above. She was praised for her hard work and perseverance in her gardening. One woman, for example, recalled that Blönduós people had often gone for a drive on Sundays to see the garden

and that it was a beautiful place. Through her gardening, Bíbí gained in time a respectable place in the Blönduós community; she was awarded a prize in 1991 by the Blönduós town beautification committee. That recognition was highly valued by Bíbí; she was very proud of her garden, feeling that it was her greatest achievement in life.

In contrast with the respect reflected in the discourse about Bíbí's garden, her doll collection was viewed in the context of her disability; it was seen as infantile, and demonstrating that she was odd and different from other people. Various stories were told of Bíbí and her dolls that reflected a certain underestimation of her: "Of course it's odd to see a grown woman playing with dolls like a little girl," said a Blönduós woman in conversation with the author. In an interview with another woman from Blönduós who remembered Bíbí well, the following remark was made: "It was often a droll sight to see Bíbí carrying one or even two dolls on her way to the garden, and one time I saw her giving her dolls coffee in the garden."

The discourse in Blönduós also indicated, however, affection for Bíbí and understanding of her interest in dolls, although it was seen as odd. One woman, for instance, said: "They were Bíbí's children and family. It was quite natural; she was so alone." Some were thus understanding about the doll collection, explaining it in the same way as one woman who attended a lecture about Bíbí at the Humanities Conference, who said: "It was the fashion in the 1950s and 1960s that women in particular collected all sorts of dolls – national costume dolls and all kinds of ornamental dolls. Why shouldn't Bíbí be allowed to do so too?"

Despite negative perceptions of Bíbí collecting dolls, most people today are impressed by her collection, and by the fact that it had been placed in the National Museum of Iceland collection. Most people were aware that Bíbí had collected dolls, though few knew the scale of her collection. Some suggested that a Bíbí Museum should be established in the future, where her dolls would be exhibited.

Thus, it is likely that the microaggressions Bíbí experienced about her doll collection led to her having partly internalized the attitudes reflected in the discourse of Blönduós people, cited above, and thus contemporary views of disability and disabled people. For a long time she was embarrassed about her doll-collecting and concealed it, but she always took pride in her garden, feeling that it had enhanced the respect in which she was held, as indicated by the discourse at Blönduós.

### **A Message from Bíbí**

In Iceland, belief in life after death has long been widespread; according to research by Erlendur Haraldsson, former professor of psychology at the University of Iceland, about 75% of Icelanders have had

some supernatural experience, and 49% had experience of contact with deceased people. Icelanders are not alone, however, in reporting supernatural experiences: in 1980 a study was carried out in 14 European countries: in most countries people had experience of contact with deceased people, or 24%. This is, however, a much lower figure than in Iceland.<sup>28</sup>

The most surprising aspect of the discourse on Bíbí's autobiography was an unexpected greeting from the other world, from Bíbí herself, via Birna Ragnarsdóttir, an Icelandic psychic living in Sweden. Our intention here is not to address the issue of belief in another world but to shed light on the diverse discourse that emerged after the publication of Bíbí's book, and Bíbí's widespread impact. Birna wrote Guðrún Valgerður a letter after the autobiography was published and this part of the chapter is based on her memory.

Birna Ragnarsdóttir got to know Bíbí in 1958 when she was four years old.<sup>29</sup> She lived in Blönduós throughout her childhood, then moved to Sweden at an early age. Birna's mother was a single parent, who worked at *Hælið* in Blönduós at that time, and Birna often accompanied her to work. She got to know Bíbí at *Hælið*; her first memory of Bíbí was from the day she arrived. Birna's mother was working when Bíbí was escorted into *Hælið*, and Birna was with her that day. She remembers holding the lift doors open for Bíbí on her arrival. According to Birna, as a child, she sensed Bíbí's pain and loneliness at that moment, and that memory is engraved on her mind. She said that Bíbí had been kind to her and that they rapidly became good friends. Birna said she often spent time with Bíbí in her room; she was permitted to play with the dolls, and Bíbí read to her and helped her learn to read. Birna is dyslexic, and she recounted that Bíbí had been endlessly patient in teaching her to read.

Birna also remarked that she had been delighted to hear of the publication of Bíbí's autobiography, but also saddened when she read about Bíbí's early years. She said she had sensed Bíbí's unhappiness, and that she had had a difficult childhood. But Bíbí, she said, never spoke about her early life. Birna was aware that Bíbí kept a diary, but she said that she kept it to herself, and asked Birna not to tell anyone about it. She said that Bíbí had often come to her over the years, both in her sleep and when she was awake. The most recent occasion was just after the publication of the book, on 27 April 2022. Bíbí's diaries, discussed in Chapter II, were discovered at Brekka on 28 April. Birna was not aware of that.

On 20 May 2022 Guðrún Valgerður received an unexpected missive in the mail: a parcel and letter from Birna. The parcel contained a doll crocheted by Birna. In a telephone conversation between Guðrún and Birna that evening, Birna said that Bíbí had liked her crocheted dolls, of which she had made many during her life. The doll she sent had dark hair, like Bíbí. On the phone Birna said that the doll was like Bíbí, as Bíbí had

wished. The doll had a small handbag, and Bíbí always carried a handbag when possible. In the handbag was a small piece of paper decorated with flower drawings, with the message:

THANK YOU GUÐRÚN

REGARDS BÍBÍ

Birna's letter follows here in full:

Nygaard 13 May 2022

Dear Guðrún.

I telephoned you on 25 April about Bíbí's book. After our conversation Bíbí sat down next to me and placed her right arm over my shoulders. *Birna dear, don't be so sad, I love you too.*

Bíbí had an eye for certain things that she found beautiful. On 27 April Bíbí woke me at 7 a.m. and asked me to help her for the last time. Of course, I said yes. Bíbí said:

NOW I CAN GO TO MEET THE ANGELS, HAPPY AT LAST

She said she had always taken good care of her books.

Regards, Birna Ragnarsdóttir.

Birna's assistance to Bíbí consisted of sending the doll to Guðrún, together with thanks for having made her autobiography known. As stated above, it was important to Bíbí to thank those she felt had helped her in some way in her life and shown her respect.

As this section indicates, belief in another world is still strong in Iceland and is part of the nation's folklore. Many Icelanders have recounted, as Birna does, that deceased people have visited them, whether in a dream or when awake, to ask them to do something for them. Such folk wisdom is full of a whole range of clues, many of which later proved accurate.<sup>30</sup>

### **Who Are the Guardians of Truth?**

The discourse about Bíbí was diverse, with many different sides and contradictions. The conversations about Bíbí revealed contradictions; through these, it is often possible to discern opposition to the dominant tendencies in the culture at any time. Bíbí was, for instance, infantilized, and described as a pitiable victim, and at the same time as a hero who overcame her disability. Bíbí's autobiography in essence turns upside down these



received ideas and attitudes about people with intellectual disabilities, and challenges the discourse, the conspiracy of silence, attitudes that lie hidden beneath the surface, and the legitimation that has characterized the discourse about this social group. Bíbí's autobiography is thus a clear counter-narrative to deep-rooted negative attitudes and stereotypes about disabled people.

Although Bíbí was subjected to abuse and microaggression, the discourse also clearly revealed that in Blönduós especially, Bíbí enjoyed the support of many people who became her friends and saw her as an equal. In contradiction to the "victim" and "fear" discourse, Bíbí was described as a helpful, warm, fun, good person who wanted to make her own contribution to the community. It is also revealed that in the community of Blönduós many people had realized that Bíbí had been misunderstood and that she had not been treated as she deserved. People also stated that behavior and attitudes towards Bíbí had changed over time, and people had appreciated her more; that during her later years she had been part of the life of the community in Blönduós. Bíbí lived in Blönduós for over four decades, and this attitude is indicative of the major changes that have taken place in society, and in views towards disabled and other marginalized groups. This may be a sign of changed ideas and increased respect for diversity, entailing respect for equality for all.

### **From the Autobiography – *Bíbí in Berlín***

*Looking Back. There are many strange things in the cow's head.*

*There are strange events in a person's life, at least there have been in mine, and there must be some purpose to it. It has sometimes felt as if various things have been whispered to me, I could mention a few examples. When I was just over twenty and offered a stay at a home in the south, if I had accepted it, what would have followed? I would never have met Dear Imba, embarked on an independent life, and cultivated my garden. To return to that chance event, so to speak, I was probably meant to remain in Blönduós, who knows? And I was probably meant to transform a filthy pit into a beauty spot.*

*There are things one doesn't foresee sometimes, but sometimes one recalls various things from younger years and reflects on them. Like when Alda and I used to play together with my toys, which weren't much, mainly the doll and her clothes that we had, there was less play with farm things, horns and jawbones, and such. But we sometimes played with broken dishes and the like when the weather was good. I remember that if I knew Alda was down at Naust, I waited in high expectation, hoping that she would come and visit me, and I was so happy when I saw a fair head appear over the hilltop at Naust farm, then perhaps a red coat*

appeared and finally all of her. I waited excitedly until she came through the gate between the homefields. But I wasn't allowed to call out to her, not when my Pa was home. I found that strange because if he saw one of his acquaintances coming and he was outside, and when the man was within shouting distance, they were sure to call out to each other, so eager to tell each other news. Yes, there are many strange things in the cow's head.<sup>31</sup>

## Notes

- 1 Michel Foucault, *The Archaeology of Knowledge and the Discourse on Language*. New York: Tavistock, 1972.
- 2 Fiona K. Campbell, *Contours of Ableism: The Production of Disability and Aabledness*. Hampshire: Palgrave Macmillan, 2009, 44–45.
- 3 Ásta Jóhannsdóttir, Snæfríður Egilson and Freyja Haraldsdóttir, “Implications of Internalised Ableism for the Health and Wellbeing of Disabled Young People,” *Sociology of Health & Illness* 44 (2022): 362.
- 4 Þí. Heilbrigðisstofnunin Blönduósi/Blönduós Health Center, SA/0134.
- 5 In total 21 interviews were carried out in the period 2018–2023 with close relatives and people who knew Bibí, see further Summary of Research Material, 8.
- 6 *Brottfluttir Blönduósingar* – Facebook page, 11 March 2022.
- 7 Foucault, *The Archaeology of Knowledge and the Discourse on Language*, 57.
- 8 Elizabeth Tilley, Jan Walmsley, Sarah Earle and Dorothy Atkinson, “The Silence Is Roaring: Sterilization, Reproductive Rights and Women with Intellectual Disabilities,” *Disability & Society* 27:3 (2015): 413–414.
- 9 Andrea Holomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach*. London: Jessica Kingsley, 2011, 29.
- 10 David T. Mitchell and Sharon L. Snyder, “Representation and its Discontents: The Uneasy Home of Disability in Literature and Film.” In *Handbook of Disability Studies*. Thousand Oaks: Sage Publications, 2001, 197.
- 11 Michel Foucault, *Power/Knowledge: Selected interviews and other writings 1972–1977*. Hassocks, Sussex: Harvester Press, 1980, 34.
- 12 Foucault, *The Archaeology of Knowledge and the Discourse on Language*, 139.
- 13 *Ibid.*, 163.
- 14 *Ibid.*, 169.
- 15 Guðrún V. Stefánsdóttir and Rannveig Traustadóttir, “Life Histories as Counter-Narratives against Dominant and Negative Stereotypes about People with Intellectual Disabilities,” *Disability & Society* 30:3 (2015): 370.
- 16 Laura Davy, “Philosophical Inclusive Design: Intellectual Disability and the limits of Individual Autonomy in Moral and Political Theory,” *Hypatia* 30:1 (2015): 132–148.
- 17 Jóhannsdóttir, Egilson and Haraldsdóttir, “Implications of Internalised Ableism for the Health and Wellbeing of Disabled Young People,” 362.
- 18 *Brottfluttir Blönduósingar* – Facebook page, 21 April 2022.
- 19 *Ibid.*, 17 May 2022.
- 20 Licia Carlson. *The Faces of Intellectual Disability: Philosophical Reflections*. Bloomington, Indianapolis: Indiana University Press, 2010, 9.

- 21 Þorsteinn H. Gunnarsson, 17 May 2022. Retrieved from <https://thorsteinnhgunnarsson.blog.is/blog/thorsteinnhgunnarsson/entry/2278923/>.
- 22 David T. Mitchell and Sharon L. Snyder, "Representation and its Discontents: The Uneasy Home of Disability in Literature and Film," 197.
- 23 Dan Goodley, *Disability Studies: Theorising Disablism and Ableism*. New York: Routledge, 2014, 44.
- 24 Jóhannsdóttir, Egilson and Haraldsdóttir, "Implications of Internalised Ableism for the Health and Wellbeing of Disabled Young People," 362.
- 25 *Brottluttir Blönduósingar* – Facebook page, 26 April 2022.
- 26 Jóhannsdóttir, Egilson and Haraldsdóttir, "Implications of Internalised Ableism for the Health and Wellbeing of Disabled Young People," 362.
- 27 *Brottluttir Blönduósingar* – Facebook page, 26 April 2022.
- 28 Erlendur Haraldsson, *Pessa heims og annars. Könnun á dulrænni reynslu Íslendinga, trúarviðhorfum og þjóðtrú*. Reykjavík: Bókaforglagið Saga, 1978, 32.
- 29 Reference published by permission of Birna Ragnarsdóttir.
- 30 Haraldsson. *Pessa heims og annars. Könnun á dulrænni reynslu Íslendinga, trúarviðhorfum og þjóðtrú*, 36.
- 31 Stefánsdóttir, *Bíbí í Berlín*, 140–141.

## 7 Inclusive Research and Bíbí's Life

### Team Bíbí

Inclusive research with people with intellectual disabilities emerged from the campaign for equality and human rights in the later 20th century as part of a disabled people's rights movement that asserts "nothing about us without us." "Meeting this aspiration came to dominate inclusive research practice."<sup>1</sup> Similarly, the United Nations Convention on the Rights of Persons with Disabilities (CRPD) requires active consultation with persons with disabilities on all matters affecting their lives, including research.<sup>2</sup> People with intellectual disabilities have increasingly been co-researchers in inclusive research in recent years. Their involvement includes recognition, and they are seen as equivalent and worthy co-researchers contributing to research. It has been noted that inclusive research has changed attitudes toward people with intellectual disabilities and has influenced the development of social and political understanding of intellectual disabilities.<sup>3</sup>

From the beginning of the research on Bíbí's autobiography, we considered it essential that part of the project should be inclusive research; it is our conviction that people with disabilities, and not least Bíbí's peers, could do better than us, non-disabled scholars – that they empathize with her and can better interpret her life experiences. So we were joined by four women, all of whom have been identified as having intellectual disabilities. Because of the research grant we received, we were able to pay them salaries and hire them temporarily as investigators in the project. Their names are: Arnbjörg Kristín Magnúsdóttir, Inga Hanna Jóhannesdóttir, Jónína Rósa Hjartardóttir, and Katrín Guðrún Tryggvadóttir. Helena Gunnarsdóttir then carried out a master's research project based on consultation and collaboration with the women, and their research in this chapter will primarily be based on the findings of Helena and the research team – "Team Bíbí" as they were called. Moreover, the chapter was prepared in consultation and with the full permission of Helena and the four women.<sup>4</sup> In addition, the topic was developed in international collaboration between

three universities as a result of this research. Team Bibí was not alone, because inclusive research groups organized by the Open University in Milton Keynes and Liverpool Hope University, UK, became part of our research effort. The collaboration culminated when Team Bibí traveled to Milton Keynes in England, and a special Bibí's Day was held in July 2023 at the Open University. The inclusive research groups met there to present and discuss their research. This day greatly affected those who participated and created a kind of emotional community between these groups.<sup>5</sup>

Bibí's life spanned much of the 20th century, and we intend here to connect Bibí's story to the present through the experiences of the four women. In other words, bringing the past to modern times. The aim is to analyze how the women applied Bibí's experience to their own lives and also shed light on the social circumstances of women with disabilities today.

### **New Research – a New Approach**

The concept of “inclusive research” has a relatively short history in connection with research on people with intellectual disabilities. The British Professor in the History of Learning Disabilities, Jan Walmsley, used the term in an article published in 2001.<sup>6</sup> Two years later, in 2003, Walmsley and Kelley Johnson used the concept in a broader sense in their book, *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*.<sup>7</sup> In the book they identified inclusive research as an approach that involves people with intellectual disabilities as active co-researchers. This allows for increased participation by people with intellectual disabilities in the research process, with a common aim to improve people's lives, as well as to understand better the research topic under consideration.<sup>8</sup>

As mentioned, inclusive research is rooted in the rights movement for people with intellectual disabilities and in life history research in the late 1980s.<sup>9</sup> In the beginning, a strong emphasis was placed on developing methods in inclusive research so that people with intellectual disabilities could be involved in the research process and incorporated as important co-researchers. Jan Walmsley et al. propose that there are signs that inclusive research is moving on from the first to the second generation. In the second generation, there is increased emphasis on demonstrating the political value of cooperative research, and that its findings contribute to societal change that matters for the wider population of people with intellectual disabilities.<sup>10</sup> Also, inclusive research is no longer first and foremost focused on people with intellectual disabilities reporting on their own lives, but also on political issues in general. There has been increased development of international inclusive research, much of it rooted in the pioneering work of the Social History of Learning Disability (SHLD) research group at the Open University, UK.<sup>11</sup> Team Bibí has collaborated

with the group in the United Kingdom, as will be discussed in more detail later in the chapter.<sup>12</sup>

Few projects of this kind have been carried out in Iceland.<sup>13</sup> Doctoral research by Guðrún V. Stefánsdóttir was the first Icelandic inclusive research study: a history group was established that included four older women born 1927–1950 who had lived in institutions for people with intellectual disabilities. In the study they recalled memories from their life experiences and circumstances at the institutions.<sup>14</sup> The inclusive research on Bíbí goes a step further, as the role of the group was to study the history of Bíbí and at the same time the contemporary history of people with intellectual disabilities, and not only to focus on their own lives. The research therefore has a unique position both in Iceland and in an international context.

As has been outlined, there has been a considerable amount of international inclusive research, but little investigation the history of people with intellectual disabilities in the same way as Team Bíbí. An exception to this is a participatory research project carried out at Liverpool Hope University about the Italian Antonia Grandini, who was born in 1830 and spent most of her life in institutions, where she died in 1872. The research on Antonia included people with intellectual disabilities, their family members, university researchers, and support staff. They based their research on a chapter from a book on medicine found in the UK Medical Heritage Library, *On Idiocy and Imbecility*, published in 1877. The book primarily contains degrading descriptions of Antonia, her appearance, and her impairment. The role of the team involved in the research was to interpret Antonia's story, how she was treated, and how it affected them.<sup>15</sup> The research on Antonia was a great inspiration for the inclusive research on Bíbí, and it will be discussed in more detail at the end of the chapter in the context of the meeting of the group Milton Keynes in July 2023.

### **Bíbí's Life and the Research Process**

The inclusive research on Bíbí's autobiography was carried out from February to October 2022. The women in the group participated actively in the entire research process, and Helena Gunnarsdóttir (author of the master's research) wrote up the results based on the following findings, having discussed them thoroughly with Team Bíbí.

The names of the women in the research group were reported at the start of this chapter, but the findings below do not refer to their names. Bíbí's story often brought up complex and vulnerable experiences in their own lives that they did not wish to share under their full name. It was thus the joint decision of the group that the results should be presented in such a way that individual details could not be attributed to each of them.<sup>16</sup>

The women were born between 1975 and 1992. They have different backgrounds, and their age range is wide. However, they also have much in common. They have all completed a vocational diploma program for people with intellectual disabilities at the University of Iceland. They are all concerned with the rights of people with intellectual disabilities, and some of them have been actively involved in a self-advocacy group (*Átak*, a self-advocacy organization for people with intellectual disabilities in Iceland). Two of them work in the open labor market, and two in sheltered workplaces for people with intellectual disabilities.

The data collection was threefold: Firstly, the major part involved discussion sessions where the group met, from February to early June 2022, for 15 sessions, for around two hours each time. At the meetings, the group read specific chapters of Bíbí's autobiography together. It was usually decided in advance which chapters would be covered, and most of the women had read the chapters before the meetings. The readings were followed by a discussion about the book. At the end of each meeting, the group summed up and recorded the main issues of discussion and what each of them thought was the most important conclusion. In addition to the meetings, Helena met the women in smaller groups. Individual meetings were held with two women who wanted to discuss sensitive issues related to their lives and felt they had not had the opportunity to do so in the group meetings. The group agreed that by this approach they could ensure that everyone was given enough space to express their views and ideas and discuss some issues more deeply.

Along with the organized meetings, the group also made two field trips. In spring 2022, the group was invited to visit the archive of the National Museum of Iceland, where Bíbí's doll collection is kept. In autumn 2022, the group went for a two-day field trip to Hofsós and Blönduós, where Bíbí's former haunts were explored. Team Bíbí also took a substantial number of photos. The group has also participated in national and international conferences and presented research findings. Worth mentioning is the participation of Team Bíbí in NNDR (Nordic Network on Disability Research), an international conference held in Iceland in spring 2023. The whole research team held a double seminar at the conference, and our colleague from the Open University joined us. Team Bíbí gave a talk at the conference where they presented their findings in English. For some of the group members, it was a huge challenge, particularly to express themselves in a foreign language. For some of the women this was a totally new experience. Apart from all this, there were countless café meetings, phone calls, and chats on a shared group on Facebook and Messenger.<sup>17</sup>

In July 2023, the group traveled to Milton Keynes for a conference at the Open University in the UK. After the conference concluded, a seminar



*Figure 7.1* Team Bíbí and the doll collection

*Source:* Photo: Guðlaug Dröfn Gunnarsdóttir.

*Notes:* In the spring of 2022, the inclusive research group was invited to visit the archive of National Museum of Iceland, where Bíbí's doll collection is kept. Guðlaug Dröfn Gunnarsdóttir was working at that time with the complete collection, which she registered, photographed and studied for her MA thesis, completed in 2023. The women of Team Bíbí, Arnbjörg Kristín Magnúsdóttir, Inga Hanna Jóhannesdóttir, Jónína Rósa Hjartardóttir, and Katrín Guðrún Tryggvadóttir, are here accompanied by Helena Gunnarsdóttir, then an MA student (second from right) and Guðrún Valgerður Stefánsdóttir at the back.

on Bíbí was convened and Team Bíbí and inclusive research groups from the Open University in Milton Keynes and Liverpool Hope University, UK, participated. Later in the chapter, we will discuss the trip and the international cooperation in connection with the Bíbí project.

### **“Attitudes Led to Exclusion”**

The attitudes that Bíbí encountered were much discussed in the Team Bíbí group. The women all found it difficult to read about the negative attitudes and harassment Bíbí was subjected to, which she often called “the peculiar attitude of the people.” The women in Team Bíbí all described having suffered negative attitudes and prejudice at some point in their lives because of their impairment. “The attitudes led to exclusion,” said one of



the groups in this context.<sup>18</sup> Bibí's childhood and schooling were widely discussed, and one of the women said:

Bibí was not allowed to go to school, which was horrible of course, but today there are also horrible things happening, and some kids don't even get to be in a class with their contemporaries, or miss out on their social life because nobody tells them what is going on. I sometimes missed events because of that, or I just wasn't thought of.<sup>19</sup>

Some of the women in the group had experienced the indifference of the school system when they were children and adolescents, as described above and reflected in the reference below:

When you have found yourself always being perceived as second-rate and different, and you get rejected over and over again, eventually you get scared of how people will react to you.<sup>20</sup>

The woman refers to bullying and harassment she suffered in school. She also talked about how, after this experience, she struggled to connect with people and trust them. She wondered if Bibí was similar and that they had this experience in common.

Bibí's description of her confirmation aroused some emotions among the research team and the fact that at the last minute, she was denied confirmation by her peers. In addition, Bibí's descriptions of rejection inside her home, especially from her father, where she was frequently hidden from guests who came by, greatly affected the women, who were sad for Bibí and the isolation and inequality she had to live with. The women pointed out that today, Bibí's situation and behavior toward her would be regarded as human rights violations and not ignored as in Bibí's time. As discussed in previous chapters of the book, microaggression is commonly a manifestation of ableism, involving repeated harassment or negative attitudes that belittle disabled people and other minority groups.<sup>21</sup> This was the case in Bibí's life, and the bullying that some of the women in the research group had also experienced is an example of this.

In addition, from the descriptions of Bibí and the women above, microaggression can be linked to microinvalidation, meaning that people's experiences of microaggression and oppression are undermined, or not listened to. This can lead to people experiencing double harassment: firstly when they repeatedly experience the microaggression itself, and again when they report it but are not believed or taken notice of.<sup>22</sup> As a consequence disabled people are often afraid to raise or report the harassment they are subjected to, and the difficult experiences related to it.

The women also wondered why Bibí had been harassed and bullied. Bibí's growth was stunted and she was always small, and then she was labeled "feeble-minded" by her family and the local community. She learned to speak late and sometimes she spoke unclearly, as she herself relates. One of the women identified with this experience and said:

It may have significantly influenced the prejudice she faced that she had difficulty learning to speak and spoke differently than other people. It is so conspicuous, and when people hear someone talk differently, they tend to decide something is wrong with that person. And then she was also short, and people without disabilities decided she was not normal and therefore not okay.<sup>23</sup>

Bibí's social status and circumstances were often discussed in the group. One of the women in the group pointed out that people may have thought that she did not deserve attention because she was a woman with intellectual disabilities who looked different from others and came from a poor family. This probably contributed to her isolation as a child and an adult. Bibí had, therefore, suffered multiple discrimination based on social class, gender, disability, and appearance, as reflected in her autobiography.<sup>24</sup> The women in Team Bibí identified with many of the factors mentioned above. They discussed their social status and identified with Bibí, even though they were aware that in many ways things had changed for the better since Bibí's time. But they had all experienced negative attitudes at some point due to the stigma of intellectual disability and they have not received the services they would have chosen. One of them said:

When we read Bibí's story, we see that many things Bibí talked about are still missing today. For example, I was on the waiting list for an apartment for over ten years until we gave up, and I went on the public rental market. Then I eventually got an apartment, but I still could not choose where to live anyway.<sup>25</sup>

Another woman made a similar link to employment, pointing out she had waited a long time for employment, as she describes below:

At first, I had to be on a waiting list, but there was not much available that I thought interesting. I tried working in a supermarket with carts and stuff like that, but it just didn't suite me. For example, I would have been interested in working in a library, but there are only few people who get in there.<sup>26</sup>

Today she works in a sheltered workplace and is satisfied with the workplace, but often finds the work not challenging for her. The women

felt it was unfair when people with disabilities do not have opportunities to work in the open labor market and thus gain experience that can be useful for their future. The women have all experienced a lack of participation in society in significant issues in their lives, such as living, employment, and education. They are low-paid women. Some of them dream of further education, but that has not been possible because of a lack of opportunities. Most of them have been on years-long waiting lists for accommodation. This uncertainty is accompanied by fear and insecurity, as Bibí often described in her story.

Unlike in Bibí's time, disabled people today have a clear right both to choose where they live and with whom, and to have suitable employment. These rights are clearly stated in Icelandic law and in the Human Rights Convention.<sup>27</sup> Recent Icelandic studies have shown similar conclusions to the experience of the women in Team Bibí. There is a big gap between rights and the reality faced by people with disabilities. Recent extensive Icelandic research on the autonomy of people with intellectual disabilities indicates that there is still a lack of options in their daily lives, where and with whom they live. Also, employment opportunities in the open labor market are minimal. Moreover, there is a significant lack of full recognition of the autonomy and right to self-determination of people with intellectual disabilities, despite their formal rights. One of the reasons for this is that people with intellectual disabilities and their families are not necessarily aware of their rights, and often they are not informed about what is going on in their daily lives. They often lack sufficient resources to enforce legal rights.<sup>28</sup>

Team Bibí also pointed out that people with intellectual disabilities need to have a support network to fight for their right to self-determination. As a result, there was considerable discussion in the group about the support and importance of their family and close support people. Although times have changed, it is still a fact that too often it is a matter of luck whether or not people with disabilities receive the support they are entitled to. Luck means having a support network, usually family, that can help people seek their rights and support them:

The support network is such a big part of life, and when attitudes in society and in the system are not always in our favor, it is so important to have that support network. Some people simply are not lucky enough to have a big, or good, support network, and that is hard.<sup>29</sup>

The women also stated that support is essential for justice and emotion, and having friends and friendship: "meeting someone who believes in you and helps you believe in yourself can change everything."<sup>30</sup> They explained that in their own lives teachers, sports trainers, friends, and other people

they had met had had a significant impact on them, in addition to their families.

Bíbí did not have a safe background in her family, but she did have support from a few friends, not least in the latter part of her life. These people changed her life for good, believed in her, took notice of her, and were concerned about her wellbeing. As a result, for example, Bíbí eventually moved out of *Hælið* and lived independently as she had always dreamed of doing. In this context, one of the women in the group spoke about a boy who went to school with her and made a big difference in her life:

When everyone was somehow against me and the bullying was going on, there was one boy who always stood by me and supported me. I will never forget him; I have even wanted to meet him later on and thank him for what he did for me. I even named my doll after him when I was little.<sup>31</sup>

In this way, the woman also identified with Bíbí's doll collecting – as Bíbí named her dolls after people she liked. Much of the group's discussion about the significant influence of attitudes was related to not being listened to, and this came up repeatedly during the meetings. The group agreed that Bíbí's opinions, desires, and expectations were not often listened to and that had significantly impacted her life. One of the women said, "No one knows us better than ourselves. We are experts in our own lives. Others are not, even if they are educated, not doctors, teachers, or anyone else."<sup>32</sup> These self-proclaimed professionals the group spoke about can be staff in the social services, for instance when they seek out family members of people with disabilities rather than speaking to them directly. This happened, for example, when Bíbí was moved into the geriatric ward at *Hælið*, where relatives and doctors had the most say and not herself. One of the women said:

Why shouldn't we know what is best for us? Who says so? Bíbí must have been incredibly tired of no-one listening to her. It is intolerable, and that is why we need to be allowed to put our side.<sup>33</sup>

The Convention on the Rights of Persons with Disabilities supports the right of people with disabilities to make decisions, both about major life events and everyday decisions.<sup>34</sup> This has often been prevented by guardianship, which is characterized by disbelief in the decision-making capacity of people with intellectual disabilities, where others, often professionals and the immediate family, feel better qualified to make decisions for the person. In discussions, it was often questioned whether the attitudes Bíbí encountered were the most significant factor in the type of

life she had. One of the women described guardianship and attitudes as follows:

You cannot take from people what they are. I am what I am. We did not choose to have a disability, but sometimes people are trying to take something away from us and put us into some predetermined box. We simply are who we are. No one can tell us what is best for us but ourselves.<sup>35</sup>

As outlined in the book's introduction, ideas about normalization and social role valorization emerged in the 1970s. These ideas dominated services to people with intellectual disabilities during Bíbí's adult life. It has been pointed out that the ideology still significantly impacts services in Iceland and in many Western countries. The influence of these ideas is reflected in the preceding reference, which has been criticized, among other things, for its emphasis on trying to make people with intellectual disabilities into "normal" or "healthy people" by training and healing them.<sup>36</sup> In this context, it has been pointed out that the requirement for a person to change and adapt their behavior to what is considered normal puts pressure on them, and not on society. They are thus accepted in society only under certain conditions, which may, in turn, adversely affect their self-understanding.<sup>37</sup> Bíbí did not escape these ideas, as the women pointed out above, and they relate to their lives.

Bíbí's account in her autobiography, where she describes moving into the geriatric ward of *Hælið* against her will, had a significant impact on the group. Bíbí recounts that when she first arrived at *Hælið*, she felt like a bird in a cage and started crying. One of the women put it this way:

I identify with being like a bird in a cage like Bíbí. She was also talking about the whole community. I feel that way sometimes, like I am not part of society. It is the whole community and what is going on in it, and then there are the others, and that is where we are.<sup>38</sup>

In this context, it is arguable that ableist attitudes mean that people with disabilities are not expected to be part of society, as most societies are structured with non-disabled people in mind.<sup>39</sup> Because of the invisibility and complexity of ableism, it can be difficult for disabled people to point it out, and this was repeatedly reflected in the stories and experiences of the women as well as Bíbí.

### **"We Are Fighters Like Bíbí"**

The women in the research team agreed that Bíbí's story had been a great source of inspiration and that she was a role model for them. They were

aware that in Bíbí's lifetime people with disabilities lacked human rights. About Bíbí's struggle, one of the women said:

Bíbí has inspired me in my struggle for human rights, and I now think differently about what we and people with disabilities are constantly fighting for. I really see her as the first woman campaigner. Not many women have drawn attention to this like she did.<sup>40</sup>

They believed that Bíbí, through her autobiography, had effectively pointed out the injustices she suffered, broken her silence, and made her voice heard, and that is a lesson to learn from her. Some of the women in the group have been actively involved in campaigning in self-advocacy organizations of people with intellectual disabilities and are aware of their rights. The group's meetings often led to heated debates on rights issues, with one of them saying to applause from the whole group: "We are campaigners like Bíbí!"<sup>41</sup> One of the women pointed out the importance of Bíbí's book finally being published, as Bíbí had wanted for so long, and the public success of it, had influenced her as acknowledgment and recognition of experiences of people with intellectual disabilities in the whole. She said, "Bíbí is a disabled woman who has written her story, and people are listening to her and learn from her; it is very encouraging for others in similar situations, and then maybe attitudes will change."<sup>42</sup>

As can be seen, the women consider Bíbí's autobiography a significant contribution, and that people with intellectual disabilities can express their voices and opinions. The group judged that Bíbí's writing had been her way to express her views and will, not least because she was not always listened to. Collaborative research has shown the importance of listening to the voices of people with disabilities, and that has contributed to changing attitudes toward the group.<sup>43</sup> The campaigner – Bíbí herself – did not have many opportunities to consult or make her voice heard during her lifetime. However, she did so through her writings, which were undoubtedly her way of protesting against her situation and have finally had an impact.

Being able to control your life, go your own way, and get support for it was a recurrent theme in the group discussions. Despite Bíbí's isolation and lack of support, she always found ways to live her own life, maintain her character, and, to some extent, hold on to her freedom. Bíbí, as has been stated, was a great nature lover who loved animals, being outside in nature, and tending her garden. In addition, she sewed for her dolls, and from the moment she arrived at *Hælið* she kept a diary, putting her feelings into words as reflected by her autobiography. The women identified with Bíbí's interests: "All this was her freedom that no one took away from her. She found her own way, and all those things give color to life, and show how great Bíbí was."<sup>44</sup>



*Figure 7.2* Research on the doll collection

*Source:* Photo: Guðlaug Dröfn Gunnarsdóttir

*Notes:* Guðlaug Dröfn Gunnarsdóttir carried out research on Bíbí's doll collection in connection with our project, published in this volume. She registered and photographed each doll. Here we see her description of one doll, as an example of her records: "Rut – 37 – The doll is 40 cm tall with long fair hair tied with a piece of pink textile fabric. She is made of plastic, with movable limbs, and blue eyes that open and close. The doll is dressed in a hand-sewn red dress, with pale-yellow trim on cuffs and neckline, and metal press-studs at the back. Two white buttons are sewn to the front of the dress as decoration. She is dressed in white fabric socks and white plastic shoes. A handwritten note pinned to the doll reads: 37 RUT BOUGHT AT GIMLI AND THE NAME IS TAKEN FROM BARNABLAÐIÐ [CHILDREN'S PAPER]. IT PUBLISHED AN INTERVIEW WITH 2 GIRLS IN AKUREYRI WHO WERE SISTERS AND THEIR NAMES WERE RUT AND REBEKKA JÓNSDÓTTIR. THAT WAS A LONG TIME AGO AND THEY ARE GROWN UP NOW. NO I'M WRONG, ONE OF THE SISTERS WAS ANNA THE OTHER'S NAME WAS GUÐNÝ."

Team Bíbí also talked about how important hobbies were in their lives, and they could relate to their value in Bíbí's life. According to them, having a hobby that one is looking forward to doing, and having the opportunity to cultivate talents and interests, was a big part of quality of life and a good life, and not least, being in charge of your own life and living in freedom. The women all have their interests, which they consider

essential in life; singing, visual arts, music, culture, good food, theatre and travel, and television programs, to name a few, and some of them dreamed of working in something related to their hobbies in the future. However, some believed that their talents and future dreams had not always been appreciated, which had kept them from seeking opportunities to pursue their dreams. In this context, they identified with Bibí. She was ridiculed and experienced prejudice because of her doll collection, and one of the women in the group said:

I think her activities were not respected because she was disabled, and maybe she was supposed to act like an adult. I am sure if she had not been disabled, people would have respected her doll collection instead of belittling her.<sup>45</sup>

The group also discussed how common it is for other people to have opinions about what people with intellectual disabilities are interested in. This could be linked to ideas of normalization, promoting the placing of people with disabilities in “proper” or “appropriate” social roles. In this case, the presumption is that children play with dolls, not grown women.

### **Empowering Collaboration – Emotional Community**

As mentioned in previous chapters, Bibí belonged to several emotional communities. She had a special relationship with each of her female friends and often with their families, who formed a particular emotional community. Bibí may also be seen as having had an emotional community with her dolls. Barbara H. Rosenwein points out that the concept of emotional community implies that social groups or individuals share common values and emotions, and are independent and ever-changing societies governed by their laws and customs. Any individual can be part of many emotional communities, as Bibí was.<sup>46</sup>

The inclusive research about Bibí created a particular emotional community among the women, characterized by empathy for Bibí and for each other. It was a strength for them to share part of their own stories in the group, and similar experiences. They felt the group established a safe space where they were able to share events and feelings they had not shared before, as one of them said: “It is good to be together and feel that you are not alone.”<sup>47</sup> In this context, the group agreed that Bibí’s story had helped them to recognize the prejudice they had experienced, harassment, and challenges in their own lives, in a new way. Although participation in the discussions was mainly a positive experience, they also felt sadness, not



least because of the injustices Bibí suffered, some of which they applied to themselves. One of them said:

It means a lot to belong to a group where you can be yourself and no one judges you. It often recalls old memories and wounds you have felt you need to discuss but have had few opportunities to do so. It feels like it is a heavy load off your shoulders.<sup>48</sup>

Participation in inclusive research can be empowering if the research material appeals to the interests of the research group members, and if people perceive themselves as active researchers and the research material is relevant to them.<sup>49</sup> One described her personal development and confidence as having increased:

I have learned from Bibí that it is possible to be a disabled woman and be confident. She was not shy, and she said what she meant. It has helped me with my shyness to get to know her like this, and I am braver about giving my opinion now.<sup>50</sup>

Thus Bibí's story often opened up discussions about events and feelings that the women wanted to share but had not necessarily shared or discussed before. They felt that Bibí's story gave them the courage to speak. For example, one of the women spoke of complex relations within a family that had burdened her. She felt that Bibí's story and the discussions in the group helped her see these interactions in a new light. She found it easier to deal with them, looking at them from more of a distance, and setting certain boundaries that she had never felt courageous enough to do before. These findings are similar to findings from a research group at Hope University, investigating the history of Antonia Grandini, presented earlier in the chapter.<sup>51</sup>

Liz Tilley, Chair of the Social History of Learning Disability (SHLD) Research Group at the Open University, organized, as mentioned before, a special Bibí's Day with research teams from three universities in July 2023.<sup>52</sup> The symposium created a unique consensus that resulted in formal and informal collaboration between these three groups. Some symposium participants kept in touch and formed friendships after the event, e.g. on Facebook. In addition, the groups commenced work on scholarly articles in which they explored the emotional impact that day had on those who participated. Together the groups reflected on the feelings that inclusive research gives rise to, the relationship between emotions, activism, and interests, and the emotional power of making connections and sharing stories about intellectual disabilities. That day saw the beginning of yet another emotional community associated with Bibí, one spanning geographical

and linguistic boundaries. The seminar was unforgettable for those of us who participated. The conversations and solidarity that arose were based on the shared experience of historical, activist research on intellectual disability.

One of the women on Team Bíbí described how she felt:

We connected immediately, and there was joy but also sadness because of how badly Antonia and Bíbí often were treated, and the stories people were telling. We share understanding of Antonia and Bíbí's lives because we have been researching together and there are also similar things we have experienced. We had something in common, and we all share interest in the same things. We are going to keep talking, and it's going to be much fun.<sup>53</sup>

### **Lessons Learned**

The inclusive study on Bíbí was intended to relate Bíbí's history to the present through the experiences of the four women on the research team. The aim was to analyze how the women applied Bíbí's experience to their own lives and also to shed light on the social circumstances of women with disabilities today. We looked at the impact on them of participation in the research and the international collaboration that was established. On the one hand, Bíbí as a person and her story was discussed, and on the other hand, the women in the group often shared their own experiences that arose when Bíbí's story was discussed. The main lessons learned from the inclusive study are:

- The findings of the research deepened our knowledge and understanding of Bíbí as a person and her history. Team Bíbí brought new aspects into the spotlight. In this context, for instance, Team Bíbí perceived strength and determination in Bíbí and her personality, and she became a fine role model for them.
- Team Bíbí and the inclusive research methodology made an impact on the rest of us and our interpretation of Bíbí's autobiography, notably when they expressed utter surprise over certain parts of Bíbí's autobiography and experience. For example, when Bíbí was sent alone to *Hælið* in Blönduós, without any help or support. We realized what a distressing event it must have been for Bíbí – a true transition – from her childhood home to this huge institution in another urban center. Bíbí all alone! Their reaction directed our attention toward this extremely important experience in her life, and our book gained a new focus.
- Team Bíbí also felt great encouragement that the publication of Bíbí's autobiography in Iceland was well received by the general public. They

saw this as an acceptance of the views and experiences of people with intellectual disabilities and at the same time of themselves, and their group.

- The research group's work on BÍBÍ's story encouraged them and strengthened them both personally and politically.
- Their discussions and analyses of BÍBÍ's life shed light on the situation of women with intellectual disabilities today. Although their circumstances are quite different from BÍBÍ's, there is still a long way to go with respect to services and attitudes toward disabled people. This can be linked to ableist attitudes that prevent people's full participation in society.
- Many of BÍBÍ's experiences seem very similar to what people labeled with intellectual disabilities often encounter today. These include discrimination, segregation, and dehumanization.
- Overall, the women found the research work positive and empowering. They found it interesting and instructive to learn about BÍBÍ's history and, in the process, to have the opportunity to draw attention to issues related to the rights and challenges facing people with intellectual disabilities, both in the past and present.
- The group established a great deal of solidarity and camaraderie, both with each other and with BÍBÍ. It was also an excellent experience for them to participate in international collaboration activities and share their research experience.

Jan Walmsley et al. have pointed out that the results of inclusive research must be political, and that findings should lead to changes in the field of people with intellectual disabilities, but also that the experience of the research process itself is no less critical, as discussed here.<sup>54</sup> It is not possible at this stage to evaluate whether the research findings improved the life and social circumstances of the women in Team BÍBÍ. However, it has been pointed out that participation in research can be empowering, as was the case in the research on BÍBÍ, not least by attaining a place of respect in the role of researcher. Furthermore, participation in inclusive research can help people cope with difficult life experiences and strengthen them as persons and self-advocates, as was the case in this research.<sup>55</sup>

Finally, the concluding text of Helena Gunnarsdóttir's master's study will be referred to below, with words from the women themselves:

From Team BÍBÍ: The inclusive study on BÍBÍ in Berlín affected us all. We got to know each other better and shared stories and experiences, some of which we'd never shared before. The work in this study allowed us to make our voices heard, and, not least, it allowed us to reflect the voice of the campaigner BÍBÍ, and we are proud of this opportunity. We are fond of BÍBÍ, and we wish we could have

known her. She was certainly such a talented, fun woman with a sense of humor in the right place. We are fond of each other, too, and although we are different in many ways, we also have so much in common. It's important for people with disabilities to participate in society, including participation in research where we can make a difference. History has taught us that our voices must be acknowledged and listened to, so that we can make a real impact on improving quality of life for people with disabilities and a better society. Negative attitudes towards people with disabilities exist, but they can be changed, and we know it can be done. The inclusive study is dedicated to Bibí's memory. She was an inspiration to all of us and impacted our lives forever. We will honor her memory and continue the fight. Adda, Inga, Jónína and Katrín.<sup>56</sup>

### **From the Autobiography – *Bibí in Berlín***

#### *Tent Making – Freedom*

*It was in 1969 that I embarked on the project of making a tent for myself. It was lined with plastic milk bags, and the inside was cotton cloth, and dense canvas on the outside, while the tent pegs and poles were made by an acquaintance of mine at Hælið. The tent wasn't ready until spring, I don't remember exactly when it was set up, but I was helped with it. It was then erected on the grounds of Hælið, in front of the window of the room I had. There was quite a hassle I had with this tent, both while sewing it and afterwards. Once, while I was sewing it, an old woman told me that I should give the tent to some child, but I didn't think so; I told her that it was more often adults who owned tents, not children. The old woman shut up, but it wasn't all over yet. If there was the slightest breeze, someone would always come and say that the tent was blowing away, which of course it wasn't, but it just scared me about it. It didn't blow away at all, but just fluttered a bit back and forth. Once on a sunny summer day, in calm and warmth, I was outside working on the tent and had to go inside to fetch something from the room, what do you think happened then? The woman who shared the room with me sort of comes towards me, and says that another old woman was supposed to have said that I ought to be sewing in cross-stitch rather than fiddling with this tent. I told her I wouldn't, as I didn't know cross-stitch and wouldn't dream of staying inside in such good weather. The old woman had little to say, and didn't talk much about cross-stitch after that. I thought this was rather foolish, as I didn't know cross-stitch, never having learned it. But as for the tent, late in the summer the tent was taken down and put in the basement at Hælið, as the weather had torn its front. I planned to repair it later, but it went differently, that's another story. That tent was never put up again. And here ends the story of the tent.<sup>57</sup>*

## Notes

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- 4 Helena Gunnarsdóttir, "‘Viðhorfin voru það sem leiddi til útilokunar’: Samvinnurannsóknin um Bibí í Berlín." MA thesis in Department of Education and Multiculturalism, University of Iceland, 2023.
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- 8 Walmsley and Johnson, *Inclusive Research with People with Learning Disabilities*, 147–149
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- 18 Ibid., 52.
- 19 Ibid., 61.
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- 22 Jóhannsdóttir, Egilson and Haraldsdóttir, "Implications of Internalised Ableism for the Health and Wellbeing of Disabled Young People," 365.
- 23 Gunnarsdóttir, "Viðhorfin voru það sem leiddi til útilokunar," 56.
- 24 Guðrún Valgerður Stefánsdóttir, *Bíbí í Berlín. Sjálfsævisaga Bjargeyjar Kristjánsdóttur*. Sýnisbók íslenskrar alþýðumenningar 29. Reykjavík: Háskólaútgáfan/University of Iceland Press, 2022. [Bíbí in Berlín: An Autobiography].
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- 56 Gunnarsdóttir, “Viðhorfin voru það sem leiddi til útilokunar,” 77.
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## 8 Conclusion

### Taking Life Head On!

#### The Impact of Ideas and Trends on Bibí's Life

Bibí's autobiography clearly reflects the influence of the grand narrative of eugenics and the medical understanding of disability.<sup>1</sup> The public discourse regarding disabled people, and not least those with intellectual disabilities, has since the late 19th century reflected the great influence of genetics and medical science, which have played an important role ever since in shaping attitudes toward this social group.<sup>2</sup> In culture and historical discourse such individuals are commonly likened to children or "invalids," or even animals, and a danger to the "race." It is even alleged that they have uncontrollable sexual urges and a violent nature.<sup>3</sup> In contrast with such stereotypes, disabled people have sometimes been presented as heroes or "super crips" who have overcome their disabilities, if they achieve something unexpected.<sup>4</sup> In the discourse analysis, based on interviews and discussions with relatives and people who knew Bibí, it was clearly noted, for instance, that she was infantilized, and described as a pitiable victim, and at the same time as a hero who overcame her disability, not least because of her garden and writing her autobiography.

Bibí was marginalized and experienced many forms of exclusion and oppression throughout her life. In childhood she was isolated at the farm, hidden from guests and visitors, deprived of the opportunity to go to school, and not allowed to be confirmed with her peers, to name a few examples. Bibí was extremely isolated at her childhood home in Berlín. It was as if she was deliberately kept away from the outside world, and the emotional communities she formed, like the one with her friend Alda, were broken – they were literally torn apart by her parents (mostly her father).

When Bibí left her childhood home, it was because there was no room for her in her father's life – there was no space for her in Berlín or in the local community. No one wanted Bibí around. As Bibí recounts in her autobiography, the intention was to get rid of her from her community. The local physician and her aunts wanted to arrange a place for her at



Kópavogshæli (the biggest institution in Iceland for the mentally retarded). Even though she never moved to Kópavogshæli, she was in a sense forced to live in another institution, *Hælið* (a retirement home): a young woman surrounded by the elderly for 17 years. After her mother's death Bíbí had to move to a new community, where she had no connections and knew no one. These were significant changes that marked a major turning point in her life. Bíbí found herself alone and abandoned in a new place, surrounded by elderly people with whom she had little in common, in an institution or hospital that was ill-suited for her.

Bíbí blames the "peculiar attitude of the people," not her impairment. It could maintain that Bíbí's understanding of disability was opposed to the traditional medical understanding, where all problems are seen in terms of the impairment of the individual.<sup>5</sup> Blaming the present state of mind of the general public reveals a modern social understanding of disability. As noted, disability only becomes a barrier because of society's negative attitudes and responses.

As has been mentioned, Bíbí left *Hælið* in 1975 to establish a home of her own and build her life independently, with the help of friends who cared about her. And around the time that Bíbí left *Hælið* new ideas were emerging, that have been associated with a normal life and social participation or *normalization*. These ideas have had a significant influence on the lives and circumstances of people with intellectual disabilities, leading to the closure of institutions and increased participation in society. Without a doubt these ideas influenced Bíbí's life in positive and crucial ways. Such ideas have been criticized *inter alia* for their emphasis on trying to make people with intellectual disabilities into "normal" or "healthy" people by training and healing them, thus maintaining the medical understanding of disabilities.<sup>6</sup> These ideas have also been criticized for seeking to place people with intellectual disabilities into "proper" or "appropriate" social roles, whereby a person is required to change and adapt their behavior to what is considered "normal." Bíbí's doll collection, for instance, was viewed in the context of her disability; she was harassed and her interest in dolls was seen as childish, and as evidence that she was odd and different from other people. During this period she faced resistance in the community but was mostly left alone. As one Blönduós resident told us, the authors of this book: "Everyone knew Bíbí, but no one talked to her." Bíbí was in this sense on her own, even though she lived in the community.

Although Bíbí was subjected to harassment and isolation, she belonged to many emotional communities that both harmed and nourished her during her lifetime. She was also excluded from emotional communities, such as with her peers during childhood and growing up. The most shocking case was when she no longer had the opportunity to bond with her childhood friend Alda. That is why it was so valuable to Bíbí to renew her

emotional relationship with Alda during the last years of their lives, and it was within the emotional community of these two that the autobiography came into being. Barbara Rosenwein's concept of "emotional communities" lays the groundwork for her book *Generations of Feeling*. Emotions are viewed as socially constructed, while emotional communities are seen as independent societies with their own norms. Rosenwein's research method involves analyzing emotional words through history, highlighting cultural and historical variability in emotional expressions.<sup>7</sup>

Despite the isolation BÍbÍ had to live with, it clearly emerged in the discourse analysis that took place as part of the research that, in Blönduós especially, BÍbÍ enjoyed the support of many people who became her friends and saw her as an equal. BÍbÍ was described as a helpful, warm, fun, good person who wanted to make her own contribution to the community. It is also revealed that in the community of Blönduós, many people had realized that BÍbÍ had been misunderstood and that she had not been treated as she deserved. People also stated that behavior and attitudes toward BÍbÍ had changed over time, and people had appreciated her more; that during her later years, she had been part of the life of the community in Blönduós. BÍbÍ lived in Blönduós for over four decades, and this attitude is indicative of the major changes that have taken place in society, and in views toward the disabled and others marginalized. This may be a sign of changed ideas and increased respect for diversity, entailing respect for equality for all.

### **Intersectionality, Multiple Discriminations, Micro-Aggression, and Slow Violence**

When someone was considered not "normal," that person's situation led to multiple forms of oppression and exclusion, as in BÍbÍ's life. The research on BÍbÍ's life was partly grounded in feminist intersectionality theories and the aim was to analyze and gain a wider understanding of how BÍbÍ experienced multiple discrimination in her life and how it influenced her self-understanding. She was labeled "feeble-minded," she was a woman, and she and her family had low social status in the community.<sup>8</sup> BÍbÍ also suffered much negative attention because of her body type. It clearly affected her self-image. Society has long valued certain body images, the so-called "perfect body." The idea of the standard female body effectively rejects the bodies of disabled women. That, in turn, has a major effect on their own body images: how disabled human beings see themselves. Their femininity is questioned because their bodies do not meet society's standards of feminine beauty.<sup>9</sup>

Like many disabled women, BÍbÍ did not have a family of her own or descendants. BÍbÍ often dreamt of what life would have been like if she had been "normal," as she puts it. BÍbÍ's dreams of a different life were



*Figure 8.1* Part of the doll collection in the National Museum of Iceland repository

*Source:* Photo: Guðlaug Dröfn Gunnarsdóttir

*Notes:* Bíbí packed up her doll collection carefully before she gave it away, writing a description of each doll, its name, and how she had acquired it on a note that she pinned to the relevant doll – most methodically.

not least colored by societal ideas about what was deemed normal in her youth and adulthood. Motherhood was central to women's identity when BÍbÍ was growing up, and it still is in many ways. So stereotypes about the perfect woman have usually been associated with motherhood. Societal attitudes toward women with disabilities have meant that they tend to disapprove of such images and are more often than not limited to being able to take on established roles of women, such as motherhood. BÍbÍ's story reveals that she was fully aware of these images regarding having children and family life. Social attitudes at the time assumed that BÍbÍ had to be "normal" in order to have children, and to a certain extent, BÍbÍ seems to have adopted this attitude toward herself. She did not fit into stereotypes about motherhood and the image of the perfect woman. When disabled women are not considered fit to have children or care for them, a negative impact on their self-image has been noted. To some extent, it can be concluded that BÍbÍ internalized ableism and set limits on her own life due to society's expectations.

The research also posed the question of how far ableism and microaggression can be discerned in BÍbÍ's life.<sup>10</sup> Microaggression is one manifestation of ableism; the term is used to describe harassment such as recurrent negative behavior and insinuations experienced by disabled people in their daily lives.<sup>11</sup> BÍbÍ's autobiography and other sources, for example, the discourse analysis, show that she was subjected to a great deal of microaggression in her daily life. For a while, BÍbÍ could hardly leave the house without disturbing and causing discomfort to non-disabled people in the environment, without her wanting it in any way. To be subjected to such aggression repeatedly, and sometimes many times a day, undoubtedly had a grave impact on her feelings and mental well-being, as many disabled people have described.<sup>12</sup>

The concept of slow violence was also instrumental in identifying power relations in which BÍbÍ was subjected to violence, whether visible or otherwise familiar or below the surface. Slow violence is a stress condition not generally associated with literal violence, but it is constantly behind the scenes and under the surface. It has a breath of impending disaster unrelated to a particular time or place.<sup>13</sup> The concept of slow violence distinguishes itself from micro-aggression by being able to be completely hidden, even to those affected by the slow violence, while micro-aggression refers to subtle, often unintentional actions or comments that convey derogatory or negative messages toward individuals. Slow violence has not previously been associated with research in disability studies.<sup>14</sup>

The two concepts proved very important to us in order to shed light on BÍbÍ's position and the impact of oppression and harassment on her identity. Our findings can thus be used to shed further light on the underlying attitudes, and how the mere presence of disabled people causes chaos and

discomfort in the social environment, due to prevailing prejudices in society. In BÍbÍ's autobiography and other documents, including interviews with her contemporaries, it can be seen that the multiple discrimination that BÍbÍ suffered had a considerable impact on her self-image at different stages of her life. It can be concluded that BÍbÍ internalized some of the oppression she suffered, not least, as mentioned before, on her image as a woman and the roles women are meant to play in society.

Scholars have pointed out that it can be difficult for disabled people to distinguish between the negative attitudes and influences they are constantly exposed to from their environment and their content. Individuals with disabilities have stated that the intersection of ableism and micro-aggression significantly affects their sense of self and can become part of it. Internalized ableism refers to the process by which individuals with disabilities come to accept and believe in the negative stereotypes, prejudices, and stigmas associated with disability, and apply them to themselves. In other words, this is when people start to internalize and believe the harmful attitudes and beliefs that society holds about disability.<sup>15</sup> English disability scholar Dan Goodley suggests that when disabled people internalize ableism, they begin to view themselves primarily in terms of their impairment: that they have less ability, are less human, and that their bodies are less attractive than those of non-disabled people. As a result, they may feel dependent on others, do not expect their rights to be respected, and do not feel capable of living independently.<sup>16</sup>

It is clear from what has been discussed here that disability, class status, gender, and body type led to multiple discrimination in BÍbÍ's life and affected her self-image. Nevertheless, BÍbÍ's unique personality, and her resilience against ableism and prejudice, were also major influences on how she defined herself, as will be discussed below.

### Critical Disability Studies Meets Microhistory

One of the aims of this book has been to explore the intellectual opportunity that is to be found in the connection between critical disability studies and the methods of microhistory. In recent decades, scholars in microhistory and critical disability studies have individually developed research aimed at people on the margins of society. However, only very few, if any, studies have combined these two fields of study, as has been attempted here.

We present BÍbÍ's autobiography as a *counter-narrative* and the whole collection of historical sources she created as a *counter-archive*. We seek to compare her rhetoric with the attitudes that characterize the dominant ideology of each period of BÍbÍ's life, the way she is depicted in contemporary official sources, and also to analyze the discourse on BÍbÍ and the interviews carried out with her relatives and contemporaries. In that way

the grand narrative of modern progress is challenged and exposed. Thus, our presentation of the past and present is expanded and enriched by the smallest details, as BÍbÍ's autobiography and other historical sources show us in exceptional clarity and detail. BÍbÍ's autobiography is thus a clear counter-narrative to deeply-rooted negative attitudes and stereotypes about disabled people.

BÍbÍ's autobiography also reflects her character and perseverance and her will to be creative all her life. In that sense she was a survivor. BÍbÍ took up arms, so to speak; she went on the offensive in her life and took matters into her own hands. She built up her doll collection, dedicated a space to herself in a no man's land where she created an ornamental garden, and she escaped from the retirement home with the help of her friend, Dear Imba. In other words, BÍbÍ became an *agent* in her own life and managed to live life on her own terms. At that time, she started to write her diary, and later her autobiography, and managed to build up a sizable library of books that she enjoyed, even though many people around her did not believe that she could read or write.

We have systematically linked critical disability studies and microhistory in this book. In particular, there are two things that make us see an opportunity to link these two theoretical approaches together: Firstly, it is the unusual life of BÍbÍ in Berlín that offers a rare opportunity to study the life of a woman with disabilities in the margins of society. Secondly, there is the magnificent collection of sources – archives – related to BÍbÍ, sources she has created during her lifetime and can be viewed as *counter-archives*. Both research frameworks have been the prerequisites for interesting studies by numerous microhistorians.

At the beginning of the book it was pointed out that, despite the rich source material that BÍbÍ created, we had to accept the subjective characteristics of these sources and deal with the gaps in our knowledge in order to understand life of BÍbÍ in Berlín. The textual analysis has been an important part of our research, deconstructing the source material BÍbÍ created and connecting it with her colorful daily life; and, yes, drawing out important aspects of both critical disability studies and microhistory in our endower.

When we read about the situation related to BÍbÍ, we discussed that the scenario could be identified with the concept of "potential history," or with what Eva Domańska calls "affirmative humanities." That concept is not about affirming and protecting a traditional notion of life. That understanding does not work well on BÍbÍ's life – on the contrary, BÍbÍ's life is so unusual that it calls for a completely different approach that microhistory often requires scholars to follow. It envisages supporting and reinforcing or empowering inspiring development, in fact, realistically building spaces to create an understanding of the marginalized individuals' situations,

finding their shared identity/subjectivity. The agreement is to find possibilities for action – potentiality – within the progressive framework of the individual life course of people who have historically been set aside.

For this reason, we can ask how to “read” the life course of BÍBÍ, a life that was such that science and any studies in the humanities and social sciences had for the longest time in the 20th century found no reason to trace it. Upfront, science did not have good tools to deal with people like BÍBÍ, not really until critical disability studies came along. Through this theoretical approach, can we elevate people with disabilities to the heights where life opens up a new dimension to our understanding of the 20th century, not just in Iceland but all over the world? With the methods of microhistory, which emphasizes both a discussion of the individual and their place in the world, rigorous textual analysis, and a focus on the gaps in our understanding of any subject matter, we have been able to achieve an understanding of BÍBÍ’s place in the world and how she struggled with difficult living conditions for most of her life.

But how do we read into the gaps in our knowledge? What microhistory requires of us is to attempt a “positive” reading of historical sources and an effort to avoid various forms of insufficiency, such as incoherence, contradiction, and logical mistakes that we will find in traditional scholarship. We are here referring to how traditional historians have viewed “important” subjects, very much in line with the male way of reading historical sources and picking out what might be labeled “important” or “great historical questions.” We argue that by pursuing research in this manner – with a positive reading of the sources – it is much more than possible to bring out the potential of any historical situation that has previously been overlooked. That has been the case with the life of BÍBÍ in Berlín and how we dealt with it, because we made the decision to believe BÍBÍ – to take her side of the story for granted, but still with our eye on the burden of proof.

Hence, the archives belonging to BÍBÍ are so unusual that they call for a different approach than we are used to. Her story is so far out on the edge that it cannot be recognized as “important” by traditional scholarship that has not been able to create space for people like BÍBÍ with standard methods of history. Our aim was reconciliatory: we assert that it is possible to take “old” archives, such as some of the archives that BÍBÍ assembled, read them again, use the method offered by potential history, free from the requirement to look for anything specific in the sources and approach the entire archive as a whole that can point us toward a “positive” image of the future. The archives created by BÍBÍ in Berlín offer us such an approach with the methods of microhistory and the aid of critical disability studies, to set the historical arguments straight and draw out the importance of telling her story in as much detail as possible.

The special element of critical disability studies is that they give us, so to speak, “permission” to look at the lives of people like Bíbí without excuses. In fact, the methods of critical disability studies and of microhistory require us to read into their understanding of life, which can open up new and unexpected perspectives into the future. The members of the inclusive research group – Team Bíbí – did exactly that; to deal with the life of Bíbí in a “positive” way. They pointed us to events and structures in Bíbí’s story that have changed our understanding of her situation. Their insight opens up our eyes to the potential that Bíbí’s story gives us for future scholarship. The dominant position of non-disabled people in society leads to a wide disparity in power, and it is, therefore, understood that it is of the utmost importance that people with disabilities step forward, make their voices heard, take their place, and contest the power of the non-disabled majority. Although Bíbí is no longer with us, her autobiography reflects her voice, her everyday life, and her resistance to inequality and negative attitudes toward her. Bíbí further integrates the perspective of critical disability studies and sharpens the picture of Bíbí found in her autobiography.

By carrying out inclusive research as part of the research project we aimed to connect Bíbí’s story to the present through the experiences of the four women with disabilities. In other words, bringing the past to modern times. The aim is to analyze how the women applied Bíbí’s experience to their own lives and also to shed light on the social circumstances of women with disabilities today. The findings of the inclusive research deepened our knowledge and understanding of Bíbí as a person and connected Bíbí’s history to the present. Team Bíbí brought new aspects into the spotlight. In this context, we can mention what a strong fighter Team Bíbí saw in Bíbí and her personality, and what an excellent role model Bíbí was to them. Their discussions about their own experiences and analyses of Bíbí’s life also shed light on women with disabilities today. Although the circumstances of the four women are quite different from Bíbí’s, many of Bíbí’s experiences strongly resemble what people labeled with intellectual disabilities often encounter today. These include discrimination, segregation, and dehumanization.

Jan Walmsley et al. propose that in inclusive research with people with intellectual disabilities, there is increased emphasis on demonstrating the political value of such research and that its findings contribute to societal change that matters for the wider population of people with intellectual disabilities.<sup>17</sup> It is not possible at this stage to evaluate whether the research findings improved the life and social circumstances of the women in Team Bíbí. However, from the results of inclusive research, we can learn that Icelandic society needs to improve in order for people with disabilities to enjoy equality in all areas of society, including education, and to choose residence and employment, as provided for in the United Nations



Convention on the Rights of Persons with Disabilities. Moreover, their self-determination is fully respected. In that respect, inclusive study is political and can have societal implications. In addition, the method, i.e. conducting research in collaboration with people with disabilities, may well encourage consultation and collaboration with people with disabilities in all areas of society.



*Figure 8.2* Bibí in a suit

*Source:* Photograph from Kristjana Heiðberg Guðmundsdóttir (deceased), loaned by her son Ásgeir Valur Snorrason.

*Notes:* A dignified teller of tales, with her sunglasses in her hand and a bag over her shoulder. Bibí had taste, and she loved nice clothes and other fine objects. She also had strong opinions about the garments she wore as a child and teenager, and was often far from happy with the clothes she was made to wear.

## In the Final Analysis

Finally, the question may be asked: what does BÍBÍ's autobiography, and other source material she made, have to say in the 21st century? And what can we learn from the reaction to her story? Firstly, the discourse analysis about BÍBÍ throws light both on past and present, uncovering negative attitudes that lie beneath the surface and are not easily discernible. Analysis of the discourse helped to uncover and explore the present in a critical manner.

While attitudes to people with intellectual disabilities during BÍBÍ's youth have little in common with contemporary views, there are many indications that negative interpretations, grounded in eugenics and medical science, are tenacious and still lie beneath the surface. Hence one may ask whether the ableist views that so devastated BÍBÍ's life remain, even today, one of the reasons why it has proved so difficult to establish an inclusive society. Through the discourse about BÍBÍ, it may be maintained that a force has been created, which can alter and develop attitudes toward people with intellectual disabilities in a more favorable direction.

According to Foucault, power is a reciprocal relationship between the governors and the governed.<sup>18</sup> Both participate through the discourse in creating legitimating principles by their consent. People with intellectual disabilities have over time had little control of the discourse about their own status in society, and hence, they have not taken part in creating the legitimating principles that have been in force. BÍBÍ's autobiography, the discourse about it, and not least the inclusive part of the research, may thus have a contribution to make in creating new legitimating principles based on the voices of people with disabilities.

## The Book – A Short Synthesis

### *The First 30 Years*

When we look at BÍBÍ in Berlín and her life, various issues stand out, especially in her autobiography, but also around other source material she created. Let us take a look at a few of these from her earlier life: some we have already mentioned, but others we have not been able to deal with. It is important to remember that BÍBÍ was in some sense marginalized, and experienced many forms of exclusion and oppression as a person that did not fit in with the rest of society. BÍBÍ was in a world of her own for most of her life, yet at the same time, she studied her environment and made an effort to take part in life as other people around her did. The hurdles she met were almost unthinkable for any human being, but BÍBÍ managed to

work things out in her favor. Here are a few points worth considering from her earlier days:

- Incredibly rich language; metaphors and hilariously constructed sentences are a characteristic quality of her autobiography.
- Self-image observations, often quite bitter and self-inflicting. But her ideas about herself could also often be quite grandiose: “I was considered promising at first. Once my mother sat with me on some slope beyond the river with another woman, who also had a child, who was a boy. Then a woman came from the countryside and started talking to them and found the girl more promising than the boy, but that changed. Unfortunately. What happened, happened.”<sup>19</sup>
- BÍbÍ could never reconcile herself with being named after her grandmother, whom she disliked. That was something she would dwell on throughout her life.
- Relationship with family and community – she was hidden away when guests came calling; the attitude toward the parents within the community was not a positive one, especially toward the father; the “little prince” (brother Steini) and his status; the use of power (spanking and verbal abuse) – a form of slow violence and microaggression.
- In the autobiography she speaks out to her prospective readers from time to time: this occurs especially when she pauses in the text and expresses her opinion on child rearing, attitudes toward disabled people, etc. She does not hesitate to give people a piece of her mind, often very forcefully.
- Scapegoat – she is blamed for everything, or that at least is her argument. BÍbÍ does not hesitate to show herself as a victim of circumstances. Also, her text includes examples of how she protested and challenged people when she felt she was unfairly treated. Those protests were not always loud; they frequently occurred in her mind, as demonstrated by the text of her autobiography.
- Connection with animals and nature – BÍbÍ finds places in nature and makes friends in the animal kingdom. She describes the livestock and includes the dog, Triggur, in the story. The same applies to cats: she tells the story of the first cat she had, and the cat she had to leave behind when she moved away from the farm Berlín – all helped her to survive.
- Puts herself in other circumstances: *What if ...?* She often makes an effort to see herself in another position; as a mother, as a wife, a woman who takes care of other children, etc.
- Humor – BÍbÍ’s text abounds in sarcasm. She did not hesitate to imply various things concerning other people’s lives. The irony is part of her approach in the text.

- Fashion and taste – Very definitive opinions on her own and other people’s clothing. She was not happy when she had to wear clothes she did not like. This was true from an early age.
- Friendship – Alda was an important person in her life, but their relationship was short-lived during her childhood years. Later in life BÍbí became a good friend of a number of people who admired her and helped her out with her many tasks and dreams – people that formed her emotional community.
- Schooling – great eagerness to attend school; disappointments, frustrations all around, because she was excluded from any real education.
- Attitude toward the social élite: doctors, clergymen, etc. – she did not hesitate to express opinions about people who were “above” her on the social ladder and give them a piece of her mind.
- BÍbí had big ambitions for her own story; it should be read by others, and she wanted to make sure that it would be published.
- Extraordinary descriptions of everyday life to be found in the autobiography. BÍbí has her eyes open, looks around, and describes what she sees. Wonderful explanations about traditional cooking, making clothes, dealing with livestock, all kinds of traditional costumes, and so on.
- Concept usage – incredibly fertile imagination, and has the means to describe her ideas with complicated concepts.
- She always writes in capital letters, which is her unusual writing style. She did not want the text to vanish, so she made sure it would not disappear by tracing each letter many times.
- BÍbí was not allowed to make drawings in her childhood home – strict rules about this and that in her life. She was not allowed to laugh or giggle. That made her father angry.
- She had a very strong sense of justice. That is something that appears in many stories she tells.
- Physical symptoms, something that is always on her mind, such as obesity, her own and others.
- Often incredibly detailed descriptions of various small events or issues. A definite characteristic of her narrative, and something that gives it a great sense of importance. We learn about so many interesting details of her everyday life that other authors rarely address.
- The slaves in ancient times! BÍbí equates their hopeless position to her own. She often felt like a slave, she thought about herself as like a slave and really meant it. Even though she sometimes sees herself as a victim of circumstances, she was in essence a doer – she did not hesitate to take action when she felt it was needed.
- The gender angle – she understood her “place” in society and what it meant to be a woman.

- After her brother Steini was born and began to assert himself, Bíbí increasingly fell into the shade, both because her parents favored him and because his personality made him popular in the village of Hofsós – people were attracted to him, and as a result, Bíbí increasingly fell into obscurity. Her isolation became even more apparent than before.
- Self-description – a broken machine! That is how she sometimes described herself.
- Menstruation – the body; very interesting thoughts where Bíbí explains the difficulties she had at puberty.
- The *self* in light of circumstances – her own conditions. Very interesting reflection on her own disabilities.
- Pithy phrases: “If Magga had her way, then Steini [her brother] would doubtlessly have gone to heaven and mingled there with angels and the chosen ones.”<sup>20</sup> Magnificent statement is just one of many.
- Bíbí is left behind when others go out to have fun. Steini is, for example, confirmed and she is not allowed to participate.
- Criticizes house construction – Bíbí had her own opinion on the new construction in Berlín, the farm they lived in.
- Gossip about adultery. Bíbí listened when people talked, even though people did not speak to her. A lot of the gossip ended up in her autobiography, which made some people who were still alive rather unhappy.
- Memories – interesting to study how Bíbí reflects on past time almost with total calm and distance from her time as a child and as an adult. She managed to take a step away from what happened to reflect on often difficult events that had taken place in her life.

Bíbí tackled life with admirable force and did not hesitate to express her opinion about a wide range of issues in her everyday life. The second part of her life marked a huge transition when she moved from the environment she knew well into a world that was totally foreign to her.

### *Later in Life*

When Bíbí left her childhood home, it was because there was no room for her in her father’s life – there was no space for her in Berlín. incredible changes occurred when Bíbí had to move to a new community after her mother’s death, where she had no connections and knew no one. These were significant changes that marked a major turning point in her life. Bíbí suddenly found herself alone and abandoned in a new place, surrounded

by elderly people with whom she had little in common, in an institution that was ill-suited for her:

- A dramatic conflict took place regarding her future, and she found it very difficult to forgive her aunts for their unwillingness to take her in and give her shelter. She had nowhere to go and did not know what to do. But she was 100% certain of one thing: she was not going into any “institution for feeble minded” as she put it.
- The transition that Bíbí faced at this time of her life was huge. In one day, she was transported into an environment that was entirely strange to her, in a place where she knew no one.
- What followed was a continuation of her isolation, in her new home, and she probably never felt so alone as at that turning point in her life. In other words, Bíbí remained for many more years cut off from the people she knew, and essentially from the entire outside world.
- Not only did Bíbí move into an unfamiliar environment, but she also moved from a tiny cottage into a huge castle-like edifice – *Hælið* – the retirement home where she was to live on the fourth floor for almost 17 years. She writes about looking out of the window when she arrived and being dizzied by the height.
- The first part of the manuscript in the autobiography is a continuous narrative of her vulnerable position in society, generally experiencing exclusion from an early age.
- She gradually came to understand what her situation was and sought to resist it through an acute analysis of her own life. After moving into *Hælið*, Bíbí seems in her narrative to emphasize various misconceptions people had about her.
- All these strangers knew nothing of Bíbí, and many were wary of her. She sets out to rectify these views, and underlines that she was something of an interloper, as a young woman among elderly people: “I can never describe how much I detested being at *Hælið*; I felt superfluous there, and what was a 30-year-old person doing among 70- and 80-year-old people.”<sup>21</sup>
- Bíbí goes on to describe her circumstances, *inter alia* as follows: “There were always persons who made my life difficult. The woman who shared my room was ... sent down to the hospital wing. After that I had the room to myself, but I was always afraid that some tedious old woman would be brought in to share my room.”<sup>22</sup> Obviously, such circumstances were not stimulating for a woman of Bíbí’s age.
- Bíbí almost always shared a room; the women who were placed with her varied in character, and Bíbí liked some better than others. When

Bíbí got on with one of her roommates, the obvious risk was that the elderly lady would die – and that was of course a regular occurrence.

- Bíbí made friends with a woman who worked at *Hælið*, who in due course invited her to move into her house, in the village. Bíbí's desire for this change in her living conditions was clear, and determined: "What I wanted to do was to live independently ... I wanted to live in an ordinary home."<sup>23</sup> Bíbí may thus be said to have discharged herself from the retirement home – not a common occurrence at such institutions! A considerable time passed before Bíbí managed to build up her own emotional community. At *Hælið* she encountered people who were kind to her, like the medical director and his wife, but during this period in her life, she struggled as she experienced a kind of slow violence: harassed by many of the residents, who made her feel unwelcome and out of place, arguing that this was not a place for her (which was, of course, true).
- Bíbí took eventually up arms, so to speak; she went on the offensive in her life, and took matters into her own hands. She built up her doll collection, dedicated a space to herself in a no man's land where she created an ornamental garden, and she escaped from the retirement home with the help of her friend, Dear Imba. In other words, Bíbí became an *agent* in her own life and managed to live life on her own terms. At that time she started to write her diary, and later her autobiography, and managed to build up a sizable library of books that she enjoyed, even though many people around her did not believe that she could read or write.
- In 1974 she moved into a room in the basement of her friend Ingibjörg Sigurðardóttir's home in the town: Dear Imba, as she called her. Bíbí lived there for nine years.
- But not everybody approved of Bíbí's decision to discharge herself from the retirement home: "Then one evening Imba came to see me and started talking to me about it, and offered me a room in her home, I was quick to accept. Unfortunately, I didn't think to keep quiet about it, but fortunately, there were only a few people I told about it. Some people started calling me stupid for leaving the home, and asked whether I knew what I was doing."<sup>24</sup>
- During this period, she faced resistance in the community but was mostly left alone. As one Blönduós resident told us, the authors of this book: "Everyone knew Bíbí, but no one talked to her." Bíbí was in this sense on her own.
- Bíbí would later move into her own small home in a good location in the village, where she remained almost until the end of her life. The house came to be known as *Bíbíarhús* (Bíbí's House).
- Bíbí was happy with this development, as her basement room was not ideal since she had difficulty cooking for herself. So, she saw no reason

to hesitate about buying the house. “Quite a lot of money was building up in the bank that belonged to me, and Imba added to it, to make up the price. I don’t know what more to say, but I was pleased to move out of the basement, in a way...”<sup>25</sup>

- Ultimately, Bíbí spent her last days back at *Hælið*, where she died in 1999, in her early seventies. The interesting life of Bjargey Kristjánsdóttir was thus at an end, but she left behind her documents, which will uphold her name long after her own time.

### From the Autobiography – *Bíbí in Berlín*

#### Reflections

*Yes, the way children are brought up varies, these days you aren’t allowed to smack them, even if they’re both cheeky and boisterous, so it affects others. I’ve repeatedly suffered from these bullies, it got so bad that I had to report it. There was a time when I couldn’t walk past the elementary school, either to go to the pharmacy or to go to the store, without all sorts of insults being shouted after me. If I shouted back and told them to stop, I was told to shut up. Would the mothers of these children want to be treated like that? I doubt it, when they had to go to the store. It was as if the kids thought I didn’t have to go to the store like everybody else, but was drifting around. I know now that there are people who ban their children from doing things and accustom them to good conduct, but not everyone, unfortunately, does. We could talk more about this and other things like children being made to guzzle soft drinks instead of milk and fish-liver oil, and eating sweets instead of healthy food, and I doubt they are dressed warmly enough. I finish these reflections here and now.*<sup>26</sup>

#### Notes

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- 3 Andrea Hollomotz, *Learning Difficulties and Sexual Vulnerability: A Social Approach*. London and Philadelphia: Jessica Kinglsey Publishers, 2011, 29.
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- 9 Clare Marriot, Caroline Parish, Chris Griffiths, Rebecca Fish, “Experiences of Shame and Intellectual Disabilities: Two Case Studies,” *Journal of Intellectual Disabilities* 24:4 (2020): 490.
- 10 Campell, *Contours of Ableism*, 44–45.
- 11 Ásta Jóhannsdóttir, Snæfriður Þóra Egilson, Freyja Haraldsdóttir. “Implications of Internalised Ableism for the Health and Wellbeing of Disabled Young People.” *Sociology of Health & Illness* 44 (2022): 360–376
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- 20 Stefánsdóttir, *Bíbí í Berlín*, 176.
- 21 *Ibid.*, 240.
- 22 *Ibid.*, 279.
- 23 *Ibid.*, 240.
- 24 *Ibid.*, 279.
- 25 *Ibid.*, 342.
- 26 *Ibid.*, 140–141.

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