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Pearl S. Buck: A Heralding Voice for the Mentally Disabled

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Abstract: This paper focuses on Pearl S. Buck's writings on disability and their impact on breaking the taboo on disabilities and advocating a more humane and supportive societal response towards the disabled. Through Pearl Buck's compassionate portrayals of characters facing mental or physical impairment, Pearl Buck served as a heralding voice for the rights of persons with disabilities. This paper not only analyzes a host of Pearl Buck's works in which the exploration of disability is a theme but also dissects how her publications and her advocacy influenced societal awareness of disability. Pearl Buck's most significant work on disability is *The Child Who Never Grew*. This child refers to Buck's daughter, Carol, who was born with a metabolic disorder called phenylketonuria (PKU). Left without medical intervention, the bloodstream of children with PKU accumulates elevated levels of phenylalanine, leading to permanent cognitive impairment. Buck struggled tremendously over what was best for Carol's care. Eventually, when Carol was nine, Buck admitted her to the Training School at Vineland, New Jersey. In 1932, Buck donated $50,000 to Vineland for the construction and running of Carol's Cottage (Trent, 1994, 233). Buck also served on Vineland's board of directors for decades. The publication of *The Child Who Never Grew* finally pushed the U.S. to break the silence on mental disability and drew public attention to this stigmatized topic. The publication of this memoir also signifies Buck's public commencement as an advocate for the mentally disabled. Through multifaceted venues such as publications, support of parents advocacy groups, and placement of disabled children through the adoption agency that she founded, Buck affirmed the values of the mentally disabled to both their families and the society in general and demanded care and support for the disabled at familial, institutional, and societal levels.

Keywords: disability studies; advocacy for the disabled; intellectual disability history; mental disabilities; *The Child Who Never Grew*; memoir

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1 *The Child Who Never Grew*: The Memoir

The Child Who Never Grew first appeared as an article in the May 1950 issue of *Ladies' Home Journal*. In this article, Nobel Laureate and Pulitzer Prize winner, Pearl Buck, shared her struggles to come to terms with and care for her daughter, Carol, who suffered from severe mental disability. Later in the year, the John Day Company published a longer version of *The Child Who Never Grew* in book form, giving all royalties of the sale to the Training School at Vineland, New Jersey where Carol was institutionalized. In addition, *Reader's Digest* published a condensed version of the story in its September 1950 issue.

It was not easy for Pearl Buck to reveal to the world the existence of her mentally impaired daughter. As Buck states in the opening of *The Child Who Never Grew*: "I have been a long time making up my mind to write this story. […] Several reasons have helped me to reach the point this morning, after an hour or so of walking through the winter woods, when I have finally resolved that the time has come for the story to be told" (Buck 1950, 5). One of the reasons for Buck to reveal probably the most sorrowful aspect of her personal life was in the many letters that she received over the years from parents with a child like hers. "They ask two things of me: first, what they shall do for their children; and second, how shall they bear the sorrow of having such a child?" (5). Buck decided to respond to these two questions by sharing what she went through personally and the actions she took as a parent of a mentally impaired child. At a deeper level, Buck also hoped that by telling Carol's story, her daughter's life was "to be of use in her generation" (5). In her words, "I resolved that my child, whose natural gifts were obviously unusual, even though they were never to find expression, was not to be wasted. […] [H]er existence as it was and is today, must be of use to human beings. In one way, if not the other, her life must count" (6). Moreover, Pearl Buck sensed the time had come to shed light on this corner of society long shriveled in shame and stigma. As she said, "I dreaded this, and do dread it. Nevertheless, the time has come. For there is afoot in our country a great new movement to help all children like her" (Buck 1950, 7).

In the early 1920s, Pearl Buck desperately searched for treatment for Carol, her visit to the Mayo Clinic in Minnesota in 1929 ended her hope for a cure (Buck 1950, 22–23). The diagnosis was so despairing that many years later, Buck could still see the scene of her daughter's diagnosis as though it took place right before her eyes (Buck 1950, 16). Buck painfully recollected that "[p]erhaps the best way to put it is that I felt as though I were bleeding inwardly and desperately" (Buck 1950, 23).

In *The Child Who Never Grew*, Buck advocates for research to discover the causes of mental disability as well as for remediable and preventable methods (Buck 1950, 8). Although it was too late for Carol, it "is not too late for many little ones,

and surely for others yet to be born. For we are beginning to understand the importance and the significance of the mentally retarded person in our human society" (Buck 1950, 7).

One of the most inspiring aspects of the book is that Buck broke away from her habitual reservation and detachment, opened herself up, and shared her sorrow as a mother of a severely impaired child. Even for a woman as strong as Pearl Buck, the process of finding a path forward was very difficult. For Buck, to have a mentally disabled child was to "live with sorrow that cannot be removed" (29). "Sorrows that can die can be assuaged, but living sorrow is never assuaged. It is a stone thrown into the stream, as Browning put it, and the water must divide itself and accommodate itself, for it cannot remove the stone" (30–31). Sometimes, Buck felt living in outright darkness. "All the brightness of life is gone, all the pride in parenthood" (27).

Pearl Buck wrote the process of finding the best possible care for her disabled child in great detail. As such, it was appealing as well as instructive for many agonizing parents whose children are mentally or physically disabled. According to Buck, the first phase of this process was disastrous and distraught "As I said, there was no more joy left in anything. All human relationships became meaningless. Everything became meaningless. I took no more pleasure in the things I had enjoyed before; landscapes, flowers, music were empty. Indeed, I could not bear to hear music at all. It was years before I could listen to music" (29).

At this stage, Buck lived through the motions and continued her writing, but "none of it meant anything" (30). However, gradually, Buck began to realize that others had learned how to live with soul-gnawing sorrow, and so could she. (31) "I suppose that was the beginning of the turn" (31). Even with this realization of living with hopeless misfortune, it was a difficult path to stay on. Buck recounts: "The sight of a neighbor's normal little daughter talking and doing the things my child could never do was enough to send me down. But I learned not to stay down. I came up again and learned to say, 'This is my life and I have to live it'" (31–32). Slowly Buck was able to move away from the abyss filled with distraught. In baby steps, she steered her energy to focus on Carol's future security. As Buck says, "the essential question remains the same for all of us who have these children who never grow up. We have to think beyond our own lives for them" (33). As Buck puts it, "The real secret of it was that I began to stop thinking of myself and my sorrow and began to think only of my child" (36). Buck began to dwell upon what kind of a world her Carol needed to live in "I realized then that I must find another world for my child, one where she would not be despised and rejected, one where she could find her own level and have friends and affection, understanding and appreciation. I decided that day to find the right institution for her" (34).

What type of institution should parents send their mentally disabled children to? After visits and observations, Buck decided happiness should be the hallmark of

Carol's future home "Happiness, I now determined, was to be her atmosphere. I gave up all ambition for her, all pride, and accepted her exactly as she was, expecting nothing, grateful if some flash came through the dimness of her mind" (39).

In *The Child Who Never Grew*, Buck gave practical and sensible advice in terms of the priorities that parents should have when choosing an institution for their children with mental disabilities. It was not the grounds and equipment that mattered. Rather, parents should look for the right people: leaders and staff who were warmhearted (40–41). Buck summarized the terrain of institutions for the mentally impaired: Private institutions were too expensive to be reachable for ordinary families. State institutions only offered the minimum. Children lived in strict and dull routines. Some state institutions were even worse than minimal, they were utterly horrific (42–43). Buck eventually chose the Training School at Vineland, New Jersey for Carol. "I saw a certain motto repeated again and again on the walls, on the stationery, hanging above the head's own desk. It was this: 'Happiness first and all else follows'" (45). Buck also talked about parents' responsibilities once their mentally impaired children were institutionalized. She highlighted the importance of regular and frequent visits (55). After placing Carol into the most suitable institution that she could find, Buck felt a sense of pride that her daughter "will be dependent on no one as long as she lives" (50–51), and "whether or not I live. I have done all that could be done."

Throughout *The Child Who Never Grew*, Buck emphasizes the value of disabled children. In her words, "There is a sacred quality of life which none of us can fathom" (28). Additionally, of God's many children, the mentally disabled ones are the most innocent (7). Buck also eloquently expressed how Carol made her a finer person: "My helpless child has taught me so much. She has taught me patience, above all else. I come of a family impatient with stupidity and slowness, and I absorbed the family intolerance of minds less quick than our own" (51). On top of that, Buck's realization of the values of the disabled went beyond the cultivation of personal merits such as temperance and patience. Living with the disabled would also help to engender a humanistic worldview in the hearts of their parents. As Buck acknowledges, "It was my child who taught me to understand so clearly that all people are equal in their humanity and that all have the same human rights. None is to be considered less, as a human being, than any other, and each must be given his place and his safety in the world" (51–52). Additionally, Buck underscores the rights of children with mental disabilities and the moral obligations of caretakers and society at large to protect their innate rights as humans and citizens. As she puts it, "[t]his mind has the right to its fullest development, too. It may be very little, but the right is the same as yours, or any other's. If you refuse it the right to know, in so far as it can know, you do a wrong" (51).

Buck, after going through all the guilt and pain that her mentally disabled daughter brought into her life, ended the book by encouraging other parents to take on the task of attending to their impaired children with pride. In an era when mental disabilities were a taboo to talk about and a shame to bury, Buck asked the parents to "be proud of [their] child, accept him as he is and do not heed the words and stares of those who know no better" (59). Rather than a burden or a curse, "[t]his child has a meaning for [the parents] and for all children." What is more, she says, "You will find a joy you cannot now suspect in fulfilling his life for and with him. Lift up your head and go your appointed way" (59).

2 Caroline "Carol" Grace Buck: The Daughter in *The Child Who Never Grew*

When *The Child Who Never Grew* was published, Carol was 30 years old and she had lived in the Training School at Vineland, New Jersey since 1929. Caroline "Carol" Grace Buck was born on March 4, 1920, to Pearl and John Lossing Buck. The Bucks' marriage lasted from 1917 to 1935 for 18 years. At birth, Carol weighed seven pounds and eight ounces and was a healthy and beautiful infant. Concerns over Carol's intellectual development began to emerge as the little girl grew; however, as a first-time mother, Buck got mixed advice and no certainty in terms of her little daughter's developmental normality. When Buck could not ignore the signs that Carol was not developing at a normal rate, she took Carol to different hospitals for examination and treatment. The doctors at Mayo Clinic in Minnesota gave the final diagnosis that Carol's mind had stopped growing for unclear reasons, and her intelligence seemed to be that of a three- or four-year-old. As a last resort to improve Carol's cognitive skills, Pearl spent over a year educating Carol herself. Realizing this was too vexing for Carol, Buck stopped her efforts.

In *The Child Who Never Grew*, Buck delineates her painstaking efforts to find the most suitable institution for Carol. Although Buck did not state it explicitly, considering the magnitude of the eugenics movement and the legalization of forced sterilization against "defectives," especially in the wake of 1927's Buck v. Bell, she must have known the stakes of putting Carol into the wrong type of institutions. In 1929, Buck enrolled the nine-year-old Carol in the Training School at Vineland in New Jersey. Not long after, Buck went back to China with John Lossing Buck, her husband at the time. Buck immersed herself in writing, a way for her to earn the annual fee expected by Vineland as well as to numb the pain of separation from her beloved daughter (Finger and Christ 2004, 51).

When Buck was looking for answers to her daughter's mental conditions, the doctors, even the ones at Mayo Clinic, did not know why Carol's brain stopped developing. In 1934 a Norwegian physician and biochemist discovered the disease Phenylketonuria (PKU). PKU is a rare inherited disorder that causes an amino acid called phenylalanine to build up in the body. A diet low in phenylalanine in the first years of life could help a patient to possibly develop normally. It was not until 1960 that Carol was diagnosed with PKU as a result of screening tests at the Training School at Vineland. By then Carol was too old for the dietary change to be beneficial (Centerwall and Centerwall 2000).

Buck saw Carol as her sorrow and hers alone to carry. With the success of *The Good Earth*, in 1932, Buck donated $50,000 to Vineland to build and maintain a cottage named after Carol (Trent 1994, 233). After Buck permanently moved back to the U.S. in 1934, she made Greens Hill Farm her home whose proximity to Vineland made her regular visits to Carol affordable. However, the existence of Carol was an utterly private matter, of which even some of her family members and close friends were kept out. As Peter Conn states in *Pearl S. Buck: A Cultural Biography*:

> She concealed Carol's existence for the next two decades. She systematically avoided any mention of her daughter in the autobiographical sketches she provided to publishers and journalists when her popularity aroused public interest just a year or two later. The text of one such pamphlet, from 1932, is illustrated with a photograph of Pearl and Janice, and concludes with the accurate but misleading statement: "I have two little daughters. One is away at school and one … is at home with us." Pearl claimed that her motive in such evasions was not shame, but a desire to protect Carol's privacy. Perhaps. However, at a time when mental illness was still powerfully stigmatized, it seems likely that she was protecting herself as well. (111–12)

In a letter to her close friend Emma Edmunds White, Buck implored her friend not to mention Carol publicly. Buck wrote, "It is not shame at all but something private and sacred, as sorrow must be. I am sore to the touch there and I cannot endure even the touch of sympathy. Silence is best and far the easiest for me. I suppose this is because I am not resigned and never can be. I endure it because I must, but I am not resigned. So make no mention of her and so spare me" (Jablow 1992, 10).

In her last years, Buck lived an isolated life, but she made efforts to keep up her regular visits to Carol. In the summer of 1972, on Buck's last visit to see Carol at Vineland, she brought with her Janice and Jean Walsh, two of her adopted daughters, in the hope that Carol would be reacquainted with these two younger sisters (Walsh 1992, 91). After Buck passed away at the age of 80 on March 6, 1973, Janice Walsh, Buck's first adopted child, became Carol's legal guardian. Janice Walsh made quarterly visits to Carol. In 1991, Carol Buck, like her mother, was diagnosed with lung cancer. After several operations and chemotherapy, Carol died in her sleep from lung cancer on September 30, 1992.

Carol Buck was buried at the Training School at Vineland's graveyard on East Landis Avenue with about 170 of the Training School's residents and a few of its employees (Marko 2022). According to Deborah M. Marko, a reporter for *Vineland Daily Journal*, most of these tombs were commemorated in rows of headstones. However, Carol's was among the handful that had their names pressed into tin markers just inside the stone wall cemetery entrance. In 2022, the tin marker was stolen, leaving Carol's grave unmarked. David Swindal, a fan who enjoyed and admired Buck's literature, was dismayed to learn that Carol's tomb was left unmarked. As a token of gratitude to his favorite author, Swindal donated a headstone for Carol's tomb (Marko 2022).

3 Mentally Disabled Characters in Buck's Writings

In her memoir *My Several Worlds*, Buck talks about her love of children and her dream of a home filled with children. However, when she gave birth to Carol in 1920, the doctor found a uterine tumor during Carol's delivery which led to a hysterectomy. As Carol was the only biological child that Buck could have, she poured her love into her beautiful baby daughter. Her bountiful maternal love rendered the subsequent realization of Carol's developmental delay ever more forbidding. Although Buck carefully kept the existence of Carol from the world, her daily struggles with caring for a mentally impaired child, concurrently carrying out other roles as homemaker, teacher, and writer, were a constant and consuming aspect of her very existence. Thereupon, it is not surprising that Buck's reckoning of disability came through in her writing in dynamic ways. These writings also reflect the journey and subject matters that Buck contemplates in terms of the values of the lives of the mentally disabled and the responsibilities of families, communities, and society in general in providing care and support to make their lives fulfilling.

In Buck's best-known novel *The Good Earth*, O-Lan and Wang Lung's elder daughter, often addressed as "the poor fool," was mentally disabled. Although the book did not provide clear causes for her mental impairment, the fact that the elder daughter suffered severe starvation in her infancy was indicated as a major contributor to her developmental delay. In real life, Pearl Buck struggled with the issue of Carol's right to live, especially when they were in hiding from aggressive rebels in Nanjing in 1927. In her award-winning novel, the protagonist Wang Lung had to face the same dilemma. Threatened by a devastating famine, Wang Lung got a handful of dried red beans from his neighbor. He gave most of the beans to O-Lan who was about to give birth. As Buck describes vividly, "[o]nly a few of the beans did Wang Lung hide in his own hand and these he put into his own mouth and he chewed them into a soft pulp and then putting his lips to the lips of his daughter he pushed

into her mouth the food, and watching her small lips move, he felt himself fed" (84). Confronted with life and death choices, Wang Lung gave the precious nutrient to his "poor fool," thereby affirming her right to live.

Additionally, Lung consistently chose to protect his disabled daughter. For example, one day his sons tricked his older daughter into the court of Lotus Flower, his favored concubine. Lotus Flower was disgusted by the disturbance of this dim-looking child. Wang Lung was offended by Lotus Flower's insulting comments about his disabled daughter and as a result treated his concubine coldly for a good while.

In her memoir, *The Child Who Never Grew*, Buck recounts in detail her painstaking search to find a home for Carol where this helpless child would be secure even when Buck passes away. This posthumous arrangement is an ultimate demonstration of a parent's love and care for a helpless child. Parallelly, in Buck's novel *The Mother* published in 1934 by the John Day Company, the nameless mother's anxiety over her blind daughter's stability was the mother's ultimate concern as her health diminished. In *The Good Earth*, Wang Lung faced the same challenge. In Wang Lung's old age, it is not his sons that were clear on his mind and close to his heart. Rather, the two persons that Wang Lung most cared about were his disabled daughter and his caretaker Pear Blossom. As Wang Lung grew weak, he "had thought many times of what would come to his poor fool when he was dead and there was not another one except himself who cared whether she lived or starved, and so he had bought a little bundle of white poisonous stuff at the medicine shop, and he had said to himself that he would give it to his fool to eat when he saw his own death was near" (Buck 1945, 335). When Wang Lung observed that Pear Blossom, a slave girl that he bought in a famine year, was kind to his disabled elder daughter, he told Pear Blossom one day what had long been in his mind: "There is none other but you to whom I can leave this poor fool of mine when I am gone […] [W]hen I die, after I am dead, you are to mix it in her rice and let her eat it, that she may follow me where I am. And so shall I be at ease" (Buck 1945, 335). Pear Blossom rejected Wang Lung's arrangement, rather she promised that she would "take this poor fool for [hers] because [Wang Lung had] been kind to [her] – kinder than any in all [her] life, and the only kind one"(Buck 1945, 336). By entrusting his disabled daughter to his faithful caretaker, Wang Lung made the best arrangement possible for his disabled daughter in the event of his passing away.

Pearl Buck wrote *The Good Earth* in 1930, by this time, she had gone through the difficult searches to secure the best long-term care for Carol. Buck was channeling all her energy into her creative writing in the hope that the royalties from her publications would help pay for Vineland's annual fees.

The Time is Noon is another of Pearl Buck's books that reveals her struggles and gradational coming to terms with being the mother of a mentally disabled child. The story of *The Time is Noon* was set in an imagined place called Middlehope in eastern

Pennsylvania. Joan Richards, the protagonist of the story, was the daughter of a pastor of the local church. The storyline centers around Joan's maturation from teenage to womanhood. The analogies between Joan's life experiences and those of Pearl Buck are hard to miss. Facing sudden family upheavals, Joan walked into a marriage of convenience with Bart Pounder, a farmer who turned out to be a clueless husband when it came to Joan's needs and wants. Joan gave birth to a son, Paul. Similar to the birth of Carol to Buck, Joan was ecstatic about motherhood: "She was having her own child, her first child, the first of many children. Children were to fill her life, all her little children. Now her life was really beginning. She had waited so long for her life to begin" (273). However, Paul appeared to be too docile to be normal: "Paul never cried. Paul was still. She coaxed him with singing and prattle and smiles. But he stared back at her quietly, his face grave, his blue eyes wandering from her face. She held him in her arms and shook him in play and he bore it patiently" (278). Like the struggling Pearl Buck in the 1920s, Joan is consumed by agony due to Paul's impairment. Joan asked herself, "But how could one live in agony day and night while a year passed, and then another and another" (296)? Joan felt she was trapped in a loveless marriage where her husband and his family were negligent of Paul's conditions. This again is analogous to Buck's experience. Lossing's mother said that Lossing was slow as a child, but he grew out of it. As such, Carol's case would be corrected with time as well. In *The Time is Noon*, Joan suffered distress from Paul's intellectual disability alone and felt totally alienated from her husband and his family. Joan asked herself, "Where could [I] go in the world? There was no door anywhere [mine] to open" (323). Buck also experienced the distress that Carol's disability brought to her marriage. In his biography of Buck, Peter Conn underlines that "Carol's tragic illness had profound consequences for Pearl and for her marriage" (Conn 1996, 79). Buck "accused Lossing of withdrawing emotionally from both her and Carol: he 'felt the child was not worth bothering about,' she said bitterly" (Conn 1996, 107).

Eventually, driven by the desire to create a home for Paul and her nephew, Joan ran away from the farmhouse that belonged to her husband and his family (323). Holding her son in her arms, Joan found a new sense of strength and freedom "The sun would swing its way around the world to bring another day. No cry or prayer of hers could stay or hasten the measure of the day and night. She knew it now and accepted all that had been her life. What had happened to her, she accepted. What was to come, she had strength to accept. She went steadily on, in freedom and alone, carrying her own burden" (323).

According to Peter Conn, Pearl Buck wrote "a fictional confession of her own marital troubles that included a heartbreaking portrait of Carol" (Conn 1996, 180). Pearl wrote the book just a few years after her father's death in 1931 while she was still suffering from the trauma of institutionalizing Carol (363). In Conn's opinion, "[t]

he novel explicitly transcribes her intimate recollections, her feelings of grievance and loss as she assessed the life she had led in the 1920s" (363). However, Buck's friends Richard and Dorothy Canfield Fisher were concerned that this book would cause controversy, especially for its unflattering portrayal of Lossing Buck's parents (180). Following their advice, Pearl put the book aside for approximately three decades until 1966 when she published the book under the title *The Time is Noon* (180). In this novel, through Joan's eyes, Pearl Buck accounts in painful detail what she excluded from *The Child Who Never Grew*, such as a mother's desperate search for any signs of comprehension and communication from her retarded child. Nonetheless, *The Time is Noon* is a story about hope. As the title indicates, the time is noon, it is the middle point. There is still the future and the possibilities despite the many losses and disappointments that life has brought on. Like Joan, Buck accepted the failure of her first marriage and the disability of her only biological child. Joan "looked ahead, into the sky. It was a deep empty bowl of pure blue light. The sun was shining through the golden dusty air. An hour ago, she had been walking this road, not dreaming of such a thing as she was doing. But now it was the one inevitable end to which life led her" (Buck 1996, 323). Like her heroine, Joan, Buck accepted what had happened in the first 40 years of her life and she was ready to embrace the future.

4 *The Child Who Never Grew*: Reviews and Reception

Upon its publication, *The Child Who Never Grew* received highly positive reviews from both the general public and professionals in the fields of health and education, especially those worked first-hand with the disabled. A July 1950 *TIME* review says, "In a simple and moving little book, Pearl Buck has told her story; other parents in like case may find help and comfort from it" (Buck 1992). In August 1950, the book made into *TIME* Magazine's Recent and Readable.

In his review of this memoir in November 1951's *British Journal of Psychiatric Social Work*, C. H. S. extols that "Pearl Buck has shown great courage in committing to print the sufferings of a mother who finds that her only child is mentally defective." He affirms that "[t]he chief value of the book lies in its honesty and straightforwardness, and parents with a similar problem may gain comfort from the author's willingness to share her burden with others." C. H. S. also points out another relief the memoir can offer to families with disabled loved ones: "One important thing Pearl Buck discovers is that a defective child, so long as it is well cared for, need not be unhappy. It is the mother who suffers, not the child. A mother who realizes this, provided her home life is happy in other ways and especially if she has other

children, will be in a better position to carry her burden and face the world." More importantly, C. H. S. extols that "[t]he author has made constructive use of her personal sorrow by taking an active interest in the causes of mental defect and in the results of training." C. H. S. especially appreciates two of Pearl Buck's statements. One of which is "those who have children who never grow … must and will work with renewed effort when they realize that half the children now mentally deficient need not have been so … " The other is "that half now mentally deficient can, with proper education and environment live and work in normal society instead of being idle in inadequate institutions." These two statements highlight the potentiality of medical research as well as education and training in alleviating the mentally disabled and their families (S. C. H. 1951).

Decades after its publication in 1950, *The Child Who Never Grew* remained one of the most popular books that college students liked to read about exceptional children. Robert M. Porter, a professor of education, taught a course titled "Exceptional Children." Based on the number of times mentioned in student reports, Robert Porter identified the books on disability that his students liked to read. Pearl Buck's *The Child Who Never Grew* made it to the top five. One student wrote that "[i]n a moving account of her own personal experience in rearing a severely retarded child, Miss Buck has successfully portrayed the pains of one who is unfortunate enough to give birth to such a child. I found this book to be extremely personal. The memory of my retarded sister's childhood has been indelibly imprinted on my mind. My mother constantly reassured me that my sister was not conscious of her condition and therefore was happy with herself. I am not sure my mother was convinced of this, however. I never was until I read *The Child Who Never Grew*" (Porter 1972).

In 1992, Woodbine House published a second edition of *The Child Who Never Grew*. It added a foreword by James A. Michener, author and recipient of 1948 Pulitzer Prize for fiction. As a friend and neighbor of Pearl Buck, Michener shared his interactions with Buck, including volunteering for the Welcome House. This second edition also included an introduction by Martha M. Jablow who provided a historical and cultural context for mental disabilities in the U.S. Additionally, Janice Walsh, Pearl Buck's adopted daughter, wrote an afterword for this reprint, providing details of Carol's life at the Training School at Vineland. Michael Rogers, who was a senior editor at *Library Journal*, wrote a review for this new edition under the title "Classic Returns." Rogers describes *The Child Who New Grew* as "heartfelt" and praises that "[t]he volume broke the taboo against raising the subject in public and laid the groundwork for the literature on the disabled that followed."

In 2011, the Editor-in-Chief of *Exceptional Parent Magazine*, Dr. Rick Rader, wrote an article titled "The Girl Who Never Grew." *Exceptional Parent Magazine* was first published in 1971. Run by a group of educators and healthcare professionals, it is a national leader in providing practical advice, emotional support, and up-to-date

educational information for families with special needs. In this article, Dr. Rick Rader hails that Buck's *The Child Who Never Grew* is an enduring classic. Rader acclaims that "[i]n 1950 Buck published a small book, *The Child Who Never Grew*. It is her views, perspectives and narrative of parenting a child with an intellectual disability. It endures. […] [I]t remains a classic in disability literature." What is more, Rader commends the contributions that the parent "pioneers" made toward disability rights. In Rader's opinion, channeling of parents like Buck who screamed for and demanded options is one of the major reasons that the *Exceptional Parent Magazine* came into being: "It's the voice of the parent's movement that started with Pearl Buck and like-minded parents. Parents who made decisions; good and bad ones, and with it, the need to share it" (Rader 2011).

Pearl Buck's conviction in the value of the lives of the disabled like Carol led to her pro-life stance. Buck explains the reasons for her anti-abortion position eloquently in "Every Life Is a Gift," her foreword to Robert E. Cooke's 1968 book *Terrible Choice: The Abortion Dilemma*. In this essay, Buck raises the following question: "As the mother of a child retarded from phenylketonuria, I can ask myself, at this reflective moment, if I had rather she had never been born. No, let me ask the question fully. Could it have been possible for me to have foreknowledge of her thwarted life, would I have wanted abortion" (Buck 1968, ix-xii)? Then, Buck responds to this harsh question: "Now with full knowledge of anguish and despair, the answer is 'No, I would not.' Even in full knowledge I would have chosen life" (Buck 1968, ix-xii). Buck gives two reasons to her decision: "First, I fear the power of choice over life or death at human hands. I see no human being whom I could ever trust with such power – not myself, not any other." Her second reason for rejecting abortion is rooted in the life of Carol. Buck claims, "My child's life has not been meaningless. She has indeed brought comfort and practical help to many people who are parents of retarded children or are themselves handicapped." She further explains, "True, she [Carol] has done it through me, yet without her I would not have had the means of learning how to accept the inevitable sorrow, and how to make that acceptance useful to others." Buck reiterates that "even though gravely retarded it has been worthwhile for her to have lived." "A retarded child, a handicapped person, brings its own gift to life, even to the life of normal human beings. That gift is comprehended in the lessons of patience, understanding, and mercy, lessons which we all need to receive and to practice with one another, whatever we are. For this gift bestowed upon me by a helpless child, I give my thanks" (Buck 1968, ix-xii). This echoes Buck's assertation in *The Child Who Never Grew* that her experience of being Carol's mother led to her conviction that "all people are equal in their humanity" (Buck 1950, 51–52). Buck summarizes her stance on anti-abortion that "in this world, where cruelty prevails in so many aspects of our life, I would not add the weight of choice to kill rather than to let live" (Buck 1968, ix-xii).

5 Pearl Buck's Dynamic Legacy as an Advocate for the Mentally Disabled

Pearl Buck's advocacy for the mentally disabled manifests in various ways throughout her growth as a parent, a writer, and a public figure. Buck's suspicion of Carol's developmental delay started when she was three or four years old and the final diagnosis was in 1929. In these five to six years, Buck began to face questions with reference to the rights of the disabled, especially their rights for life, for long-term security, and for happiness. Although during this time Buck kept Carol's disability as private a matter as possible, her humanist understanding towards disabled persons was maturing. Her compassionate portrayal of the disabled children in her fictional writings such as *The Good Earth* and *The Time is Noon* was parallel to her personal convictions that the lives of the disabled persons not only counted but offered many gifts to their families, the persons they have touched, and the society at large. Buck's actions followed her beliefs. The success of Buck's writing career not only enabled her to become a generous donor for Vineland but she also served as a member of Vineland's board of directors for decades (Finger and Christ 2004, 50). Moreover, Buck became an active volunteer and spokesperson for National Association for Retarded Children (Wehmeyer 2013, 181).

With the publication of *The Child Who Never Grew* in 1950, Pearl Buck came out of the shadow of sorrow and guilt, opening herself up to advocate for disabled children who could not speak for themselves. In *Pearl S. Buck: A Cultural Biography*, Peter Conn accolades that *The Child Who Never Grew* "helped to remove the stigma attaching to retardation, the sense of shame that has always been the second heavy price that families with retarded children have paid" (319).

Notably, Pearl Buck took on a very personal approach to helping individuals and families navigate the complexity of disability. According to Peter Conn, Pearl received letters from parents worldwide. One letter was from Madame Charles De Gaulle, who empathized with Buck as her youngest daughter, Anne de Gaulle, suffered from Down syndrome. Peter Conn highlighted that Buck "answered every letter personally, often at great length, displaying a compassion and sensitivity that were often less noticeable in her other correspondence" (319). Besides, Conn states that "[p]hysicians and public health authorities also wrote, congratulating Pearl for her courage, and telling her that she had permanently changed the terms of public discussion" (319). Furthermore, Conn underscores Pearl Buck's support for parents who were fighting for their disabled children: "Typically, she also took a leading part in organizing the parents of retarded children as political lobbyists. 'Our children,' she often said over the next several years, 'had to have voices because they are silent; they cannot speak for themselves'" (319).

In her introduction to the 1992 Woodbine House edition of *The Child Who Never Grew*, Martha M. Jablow ratifies Conn's point of view. As Jablow asserts, "When a woman of such prestige and achievement 'went public' about having a mentally retarded child, the floodgates burst open. She received mailbags of letters from readers whose lives, like hers, had been affected by mental retardation. Some readers even showed up on her doorstep to meet her personally, and she patiently took time to talk with them" (3). Pearl Buck showed extraordinary attentiveness to letters from readers whose family members suffered mental impairment. Jablow cited a letter that Buck wrote to a mother who was organizing other parents to advocate for their mentally impaired children. Pearl restated her belief that many of the mentally disabled children could be aided to become useful citizens "if they had special training and could work in a protected environment" (14). Also, she approbated her support for parents-initiated advocacy groups: "I am deeply interested in such groups as yours, for it is the parents of retarded children who must awaken our people. […] The parents must stir up the community not only to give these children every opportunity for life, but also to treat them as human beings" (Jablow 1992, 14–15).

In addition to encouragement via correspondence, Pearl Buck extended hospitality and understanding to parents who showed up at her door for advice and support. In Buck's 1954 memoir *My Several Worlds*, she describes such visits:

> Other feet beat a path to my door, too, not because I have made excellent mousetraps or anything else that surpasses the products of others. No, it is because of something that my invalid daughter has done for me. I open the door and there stand two parents, mother and father, and with them a child, a little boy or girl, and I look at the child and I know why they are here. The child is retarded.
> "Come in," I say.
> They come in and I open the big old French armoire in the living room that serves as a toy closet for the Welcome House children when they come to spend the day, or for grandchildren and neighbor children, and the little child amuses himself while the parents tell the story I know too well. It is part of my own life, repeated again and again, and when it is told, we consider together what the child's future shall be, where and how. (405)

Buck knew the limited options that the parents had, but she chose to offer what she could, including being an empathetic listener. In her words, "[m]ost of the parents are too poor to afford the fees of a private school, and even if they can afford them, can they also afford to arrange for the terrifying future when perhaps they are dead and the child lives on? We talk for hours, the child growing hungry, and I fetch cookies and milk and we talk again. There is no solution and I know it, but still we talk" (Buck 1954, 405).

Buck was keenly aware of the minimal resources that public schools and state institutions had to offer to these distressed families. She laments

> For the most neglected children in our entire nation are these little ones whose minds have been injured by some accident before, during, or after birth, the ones who cannot grow. Public schools too seldom carry the classes which would teach them what they could learn, for all of them can learn something and be the better and happier for it, and with what relief to their sorrowing families can scarcely be expressed. But the Boards of Education are oblivious or hard pressed, budgets are strained, and so nothing, or very little, is done for these American citizens. […] And when their parents leave them they are left to shift with unwilling relatives and hostile communities, and they live and die in a daze of misery. (Buck 1954, 405–406)

Seeing the impossibility of imminent support from public sources, Buck encourages the family, especially "the parents together rise up to defend their own" (Buck 1954, 470). Buck "appeal again to the family, for family must be the individual's stronghold, his safety and his shelter, and there is no welfare agency or state institution or public organization which will do so well for the needy child, or adult for that matter, as the concerned family. Somehow the American family must be taught responsibility for its own again" (Buck 1954, 406). Comparing American nuclear family to China's multi-generational extended family, Buck calls for the support of extended family members and relatives in the care of mentally disabled children: "Where are the grandparents, if the parents have disappeared, and where are the aunts and the uncles and the cousins? The child belongs to them, too, and in China they would have kept the child with them. Here, alas, we have no longer the large family feeling that shares responsibility for all its members. It is the child in our society who bears the brunt of the fragmentation of our family life" (326).

In actuality, Pearl Buck's appreciation towards the acceptance and openness that the Chinese held to the disabled dates back to the days when she was a missionary wife in 1920's central China. In her words, "I had grown up among the Chinese, who take any human infirmity for what it is" (Buck 1950, 18). In Buck's opinion, the Chinese did not ignore their impaired, who came and went among others and were accepted for themselves. It was her own countrymen's unkind words that compelled Buck to shield her daughter. In *The Child Who Never Grew*, Buck recounts the incident on a street in Shanghai: two well-dressed young American women stared at Carol and when Buck and Carol had passed, one of them said to the other, "The kid is nuts!" Buck never heard this slang and had to ask someone to find out what it meant. Buck laments: "Truth can be put into brutal words. From that day, I began to shield my child" (Buck 1950, 19).

Another account of Pearl Buck's interactions with parents of disabled children is in her 1961 memoir *A Bridge for Passing*. In May 1960, Buck was in Tokyo as a consultant for a film based on her story *The Big Wave*. Janice Walsh called Buck to notify her that her bedridden husband, Richard Walsh, had just passed away. Grief-stricken, Pearl Buck rushed back home through Honolulu. As Buck was standing in the line for customs inspection, a male customs official came to her and

asked her to step aside. Buck was surprised. Then in a low voice, the man told her that he had a retarded daughter (Buck 1961, 83).

> Ah, now I knew why he had drawn me aside! I am accustomed to having people take me aside and tell me this. Everywhere in the world I have had the same experience.
> "I want to tell you – I have a child – "
> "Tell me about her," I said.
> I listened while he talked, and though I heard every familiar word, I was filled with inner wonder. How could it be that at this very moment when I needed desperately to be made to want to live, this man should be here, recalling me to life? For much of my life has been spent in working with and for those who are the parents of retarded children and for their children. This has been my destiny. Yet in the last hours, ever since my daughter's voice had come to me over the telephone in the early morning in Tokyo, I had not once remembered this part of my life. Now here it was, claiming me again. (83)

At the end of their conversation, this father said, "I'll never forget you. This is my lucky day. Wait till I tell my wife. She won't believe me. It's a miracle" (84). Buck was as grateful and said to herself, "It was a miracle for me, too" (84). At a moment of great loss and sorrow, the trust and appreciation from a father of a mentally disabled child reminded her of her "destiny" to help the families with disabled children (84). This incidental reminder "claimed" her, uplifted her from the abyss of losing her husband, and filled her with a sense of purpose. This account makes it clear that to be an advocate for the mentally disabled has become an ingrained part of Pearl Buck's identity.

After *The Child Who Never Grew*, Pearl Buck continued publishing as well as introducing books that aimed to increase public awareness with reference to the rights and needs of the mentally disabled. In 1952, the John Day Company published a book series on mental disabilities from professionals in such fields as medicine, public health, social work, and special education. Among them was Dr. Abraham Levison's *The Mentally Retarded Child: A Guide for Parents*.

As professor of Pediatrics at Northwestern University Medical School and professor and head of the Department of Pediatrics at Cook County Graduate School of Medicine, Levinson was a highly respected expert in the field of pediatric mental disabilities. Pearl Buck wrote a glowing introduction for Abraham Levinson's *The Mentally Retarded Child*. In her introduction, Buck points out the great needs that Levinson's book fills. In her words, "Parents of retarded children have long needed a handbook wherein to find guidance for their peculiar problem. Out of his long and wide experience, Dr. Levinson now meets the need with information in terms that the lay reader can understand, and with wise advice" (Buck 1952, 7). Buck reiterates the lack of research on mental disabilities and the work cut out for finding their causes or their possible cure. She then calls on the parents of mentally disabled children:

> When accident brings parents into the arena of disaster, where many others are to be found, the impulse to shut one's self away, to give up, to ignore the facts, must be strongly and sensibly resisted. Experience must be put to general use. For it is the tradition of an intelligent and modern civilization to accept facts as they exist, to learn what they mean, and then to search for solutions. Primitive and degenerate civilizations eliminate the weak, the different, the dependent, but advanced civilizations have always cared for the weaker members as a matter of course. Indeed, the test of a civilization is to be found in such attitudes. Religions of every people teach the same principles of mutual support and co-operation, and it is interesting to know that those civilizations which have cherished most tenderly the young and the aged are those which have continued to live, long after their more Spartan contemporaries have ceased to exist. (7)

Buck advocates for undertaking the research and study necessary for understanding the many forms of mental retardation and the prevalence of the problem. She insists that "[s]o little has been done as yet, that all parents who are drawn into this vast family of the afflicted should feel it their duty and privilege to contribute what they can of time and money to those who are best fitted to carry on the actual work of research"(8). Furthermore, Buck reaffirms that "[i]n so doing, the parents themselves will find their greatest comfort. If sorrow has any meaning, it is that its causes may be removed so that others need not suffer a like fate"(8). To conclude, Buck "urge[s] upon all the parents who read it that they let the little child who now crushes their hearts with grief lead them into new determination, that despair may be changed to energy, in the hope that other children yet to be born may enter life without the handicaps from which perhaps their own child can never be freed" (Buck 1952, 8–9).

On January 1, 1965, *The Gifts They Bring: Our Debt to the Mentally Retarded*, co-authored by Pearl Buck and Gweneth Zarfoss, went into print. This book argues that most of the mentally disabled persons can achieve some degree of independence given proper training and support. Moreover, the authors convey strongly the gifts that the mentally disabled can bring to their families and communities by giving and receiving love. In the authors' opinion, a disabled child "makes the hearts tender, the hearts of his parents and his brothers and sisters. He teaches them lessons of patience and consideration, those qualities so essential for every good human relationship" (146). Consequently, "[l]ove enlarges the heart so that what is done for one small retarded child will have its rippling repercussions in benefits for other damaged children and handicapped person, and thus warmth and mercy and justice for the one and the few will extend to all" (149). Elizabeth P. Nichols gave a resplendent review for this book on May 5, 1965's *Library Journal*. Nichols states that "[t]hroughout this book, the writers elaborate the theme of the title. Some of these gifts are the contributions made by mentally retarded to our knowledge of psychological testing and educational theories, medical research, rehabilitation, and

institutionalization." She also affirms that "[t]his will be rewarding reading for families and friends of retarded persons and for professionals working with them" (Nichols 1965).

It is noteworthy that Pearl Buck's advocacy for the disabled is multi-faceted. It encompasses not only her personal commitment such as contributions to the Training School in Vineland, and support for parents with disabled children but also the institutional leadership she provided through the Welcome House. In Soojin Chung's article "Mother of Transracial Adoption: Pearl Buck's Special Needs Adoption and American Self-Criticism," he emphasizes that the Welcome House, founded by Pearl Buck in 1949, expanded its program to include the adoption of other special-needs children, including not only mixed-race children but also children with disabilities, older children, and African-American children (349). Chung further clarifies that for the Welcome House, special needs adoption involved children who were "hard to place" due to factors such as their race, mixed heritage, physical and mental disabilities, and age or sibling groups. According to Chung, the Welcome House's efforts to expand the boundaries of adoption were trailblazing. Chung provides the historical contexts that, according to a report from the Child Welfare League of America, the oldest child welfare organization in the United States, even in 1948, half of the country's leading adoption agencies completely ruled out placing a child who had a mentally sick biological parent, let alone placing children with mental disabilities themselves. Furthermore, 80 % of the agencies reported that they would place only the "perfect" child with perfectly matched adoptive parents (351).

No question that Buck's vision on adoption was ahead of her time. As Chung underscores, Buck argued that adoption was appropriate and necessary for any child without family ties, regardless of their age, race, and physical or mental capacity. In Chung's opinion, Buck was rightfully critical of the dominant model of her time: Buck perceived that the real hindrance to adoption was not that these children were unwanted but the demand that children and prospective adoptive parents must match (352). Chung also details how Buck used her status as a well-known author to request her readers to pay attention to special needs adoption, children with disabilities, and the poor social conditions that failed to support single mothers (352). In Chung's opinion, through a multitude of anecdotes and case studies, Pearl Buck succeeded in proving that older children, children with mixed racial backgrounds, and children with disabilities could become members of happy families. Chung concludes that Buck's "writings and speeches steadily changed the public's perception of special-needs adoption by providing continuous evidence that such children were 'adoptable'" (354).

6 Conclusion

The publication of *The Child Who Never Grew* in 1950 symbolizes the commencement of Pearl Buck' public advocacy for the mentally disabled. Over the next two decades, she was a strong heralding voice for the rights and welfare of the mentally disabled. Since the 1950's the cause for the disabled has evolved from objecting to social segregation and overcrowded institutions to actualizing inclusive and equitable and inclusive communities for people with disabilities and their families. Nonetheless, Pearl Buck's legacy as an advocate is acknowledged today. The state governors play an important role in initiating policies to provide educational, social, and employment opportunities for the disabled. In their public education campaigns on disabilities, they commend Pearl Buck's role in shifting public attitudes. For example, the Minnesota Governor's Council on Developmental Disabilities states that two books published in the early 1950s – Pearl Buck's *The Child Who Never Grew* and Dale Evans's *Angel Unaware* – had "an enormous impact on the public perception of mental retardation." Furthermore, "[t]hese public acknowledgments of a child with mental disabilities were unprecedented. Here were two of the most famous women in America unashamedly telling the world about their daughters and how they had loved them. Mental retardation had come out of the closet" (The Minnesota Governor's Council on Developmental Disabilities 2024). Likewise, the Office of the Texas Governor declares, "The Pulitzer Prize-winning American novelist Pearl S. Buck, best known as the author of *The Good Earth*, also helped to raise awareness of the challenges faced by people with intellectual disabilities. It was her experiences with her own daughter that led Buck down a path that helped shape the future for people with intellectual disabilities." Furthermore, "it was her impact on other parents of children with intellectual and developmental disabilities for which she is most remembered by disability advocates" (Office of the Texas Governor 2013).

More importantly, Pearl Buck inspired generations of parents with disabled children to speak up on behalf of their children's welfare. Some of them grew to be dynamic leaders of the movement for rights and inclusion for the disabled. Their journeys as trailblazers and strong leaders best exemplify Buck's vibrant legacy.

Pearl Birnbaum Hurwitz (1907–1993) was a graduate of Radcliffe College and wife to Dr. David Hurwitz, a physician and professor. The second of her four children, Stephen, was mentally disabled. In 1957, Pearl Birnbaum Hurwitz's essay "The Mentally Retarded Child – Changing Community Attitudes" was published in *Radcliffe Quarterly*. Hurwitz began her essay with a quotation from *The Child Who Never Grew* to explain her decision to speak publicly as a parent of a mentally impaired child:

> It is not easy – even after nineteen years – to speak openly about a situation in one's family which is somehow considered shameful, guilt-ridden, and to be hidden. It is easier now. As Pearl Buck says in the introduction to *The Child Who Never Grew*, the eloquent story of her own retarded daughter: "I have sometimes wondered, as the years passed, whether the moment would come when I might feel that my purpose for my child must include the telling of her story. I dreaded it. I still dread it. Nevertheless, the time has come, for there is afoot in our country a great new movement to help all children like her. (Hurwitz 1957)

Like Buck, Pearl Hurvitz wanted to give her voice to push forward a movement that would help all children like her intellectually disabled son. Hurvitz continued to ask the question as "[h]ow to orient the general public to a real and growing understanding of the rightful place of the mentally retarded in our present society?" Pearl Hurvitz quoted The World Health Organization's "Report on the Mentally Subnormal Child": "Popular education can be given in a number of ways … but few things can do more to break down the mistaken stigma attached to mental subnormality than the public declaration by respected members of the community that they, too, have handicapped children." Following Buck's steps, Pearl Hurvitz shared Stephen's story. She joined other parents, with the initial purpose "to achieve something for my child." However, it did not take her long to dive into the cause to promote the welfare of the mentally retarded children. Eventually, Pearl Hurvitz grew into an excellent organizer and became the founding president of The Massachusetts Association for Retarded Children, Inc. (today's ARC of Massachusetts). She also served for years on the Massachusetts special commission to study facilities for retarded children in the Commonwealth. Pearl Hurwitz passed away in 1993 at the age of 86, but her legacies in the movement to provide services and support for children with disabilities and their families are not forgotten. In 2014, the Pearl Birnbaum Hurwitz Humanism in Healthcare Award was established through a generous gift from Dr. Ronald Arky, Daniel D. Federman Professor of Medicine and Medical Education at the Harvard Medical School. The award is presented annually to a woman who exemplifies humanism and has advanced, through her scholarship, advocacy, leadership or work, the well-being of underserved or at-risk populations in the healthcare arena (Gold Foundation).

Another story to illustrate Pearl Buck's vibrant legacy is that of Emily C. Bloom's. Bloom is a writer, a teacher, and a mother of a disabled child. On May 20, 2024, Bloom published "What Pearl S. Buck's Memoir Can Teach Parents of Disabled Children" to contemplate on the impact and legacy of *The Child Who Never Grew*. Bloom's article demonstrates how Pearl Buck's legacy is inspiring a new generation of parents with disabled children to pursue their dreams and enrich the conversations with relation to family, motherhood, disability, and gender. When Bloom's disabled daughter (with congenital deafness) was one year old, her mother handed her a worn-out copy of Buck's *The Child Who Never Grew*. As Bloom's brother had microdeletion syndrome,

Bloom immediately recognized the significance of her mother's act. "The act of giving me this book felt significant" (Bloom 2024), Bloom said, "like an inheritance that she passed on to me. She, as the mother of a child with disabilities, passed it on to me, another mother of a child with disabilities" (Bloom 2024). Bloom's mother wanted Emily to have the book because she thought it would help her daughter on her "path navigating the emotionally complex and bureaucratically complicated life of a parent of a child with disabilities" (Bloom 2024). Emily Bloom thinks highly of *The Child Who Never Grew*. As she puts it, "[e]ven as it has been supplanted by other, more up-to-date memoirs and accounts of motherhood and disability, Buck's book stands as one of the first examples of a prominent woman speaking publicly about her experience mothering an intellectually disabled child" (Bloom 2024). Emily especially appreciates Buck's honesty. In her words, "Buck's book stands out for its emotional forthrightness" (Bloom 2024).

Buck's choice between a writing career and motherhood is especially meaningful to Bloom. Emily Bloom sees *The Child Who Never Grew* both "as enticement and a warning" as Bloom herself has to reconcile her writing with her responsibilities as a mother. As Bloom puts it, "[i]f this balancing of competing needs is difficult for any writer-mother, it is doubly difficult for a parent of a child with disabilities whose needs may be more persistent or more complex." In Bloom's opinion, today, when so much social support has been stripped away in our society, parent narratives can have a huge impact on the future of disability rights and policies.

Like Buck, Bloom bravely shared her experience as a mother of a disabled child through her writing. In April 2024, Bloom published her memoir *I Cannot Control Everything Forever: A Memoir of Motherhood, Science, and Art*. Bloom says, "Like Buck, I wrote because I felt that the stigma of privacy and shame was worse than the risk of saying the wrong thing. I did it because I did not want to sacrifice my writing self entirely to my mothering self. And I did it not to speak on behalf of people with disabilities, but rather, to connect to other parents who might be navigating similar challenges … and looking for a voice like I had in my mother and my mother had in Buck."

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Bionote

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