

Stars step into the spotlight at a place where the actors, artists, and writers just happen to have disabilities.

FRONT & CENTER

By Dara Moskowitz Grumdahl

Photographs by Stephanie Colgan

ALLISON BALDRIDGE HAS BIG BLUE-GRAY EYES and a grin like a cartoon smiley-face sun breaking through sad clouds. She also has a difficult form of mental retardation that leaves her stand-still stunned by everyday negotiations. Like how to get a coat on when there's something in your hand. Baldrige needs someone to help her navigate almost every hour of every day. She's always been like this, and she used to have seizures, too. What is the right place in the world for Baldrige?

And Nik Neiss, born with Down syndrome and a host of medical troubles, including a pharyngeal flap that won't shut to allow a standard voice, and a hairless face that leaves him with a resting expression of having just been startled. What is the right place in the world for Neiss?

And Marisa Bingham, who has no-nonsense green eyes, who donated her long chestnut hair to Locks of Love, and who is noted by most people for a head that is swollen with hydrocephaly and a body twisted by spina bifida and seizures. A 26-year-old woman who

REWRITE THE FIRST THREE PARAGRAPHS:

ALLISON BALDRIDGE HAS BIG BLUE-GRAY EYES and a welcoming grin that shows the confidence that she has earned as a Target Store employee and a performing artist. Though she was born with a developmental disability and has had a history of seizures, Allison has made great strides toward independence. To assist her, Baldrige is supported by caregivers and job coaches to help her navigate daily living.

Nik Neiss has a commanding presence, whether bowling with friends, writing a screen play or performing before hundreds of people. Nik was born with Down syndrome and additional complications that affect his speech. Nik has worked hard at the art of being understood. He carries a pencil and paper in his fanny pack in case he needs help conveying his thoughts.

Marisa Bingham, while quick witted, is also very loving, having donated her long chestnut hair to Locks of Love. Marisa was born with spina bifida and seizures, and motors around in an electric wheelchair. Her vision sees no barriers, only opportunities to help and to entertain others. She relishes the evil parts she seems to always get in the plays—evidence of her complex personality.

REPLACE WITH "CHALLENGES"

Everyday tasks are difficult for Allison Baldrige, but she's all smiles at play practice.





Norm Munk, right, CEO of Partnership Resources, helps clients find their public voice.

SEE NOTE, PREVIOUS PAGE.

maneuvers the world with a motorized wheelchair and snappy one-liners—“I’m a giver, that’s all I do”—that she may or may not understand. What’s the right place in the world for Bingham?

Munk has the answer: onstage. Munk is the CEO of Partnership Resources, Inc., an agency serving about 275 adults with developmental disabilities in Minneapolis and St. Louis Park. Munk has produced a remarkable documentary called *Born for the Stage* chronicling the theater work of Baldrige, Neiss, Bingham, and others served by the agency. The film follows them as they put on a production of *Hairspray*, the musical adaptation of the 1988 John Waters movie starring Ricki Lake, Sonny Bono, and Deborah Harry.

The play stars Baldrige as Tracy Turnblad; Neiss as Seaweed, the African American dancer who teaches Tracy all the winning moves; and Bingham as the shallow mother Velma Von Tussel. *Born for the Stage* follows them and their fellow actors through auditions, rehearsals, dress rehearsal, and finally the big show. The production—with Baldrige in a sky-high blond beehive wig, Neiss dancing with loose abandon, and Bingham wearing marabou feathers that stream as she glides over the stage in her wheelchair—ran for two nights at MacPhail Center for Music in Minneapolis and sold out.

Waters was so moved by raw footage of the event that he reached out to the group when he was in town. “It was beautiful, what you all did. It was touching,” Waters, the ultimate outsider’s outsider, told them in a meeting that also appears in the film. “I think you should start touring with it!” Now finished, the movie is being shown at the Manhattan Film Festival and broadcast on TPT-TV Channel 2.

ZOMBIE ELVIS

Since their brush with fame, the Partnership Resources actors have moved on to other projects—and other aspects of the dramaturgical arts. They are being led in the creation of one-act plays, which will be performed this month at The Ritz Theater in Minneapolis.

Neiss wrote a dark, of-the-moment comedy called *Zombie Elvis*. As the play opens, Elvis is innocently going about his business—he’s a funeral home owner—when his nemesis appears: “I am going to kill you because you are fat and puffy,” his nemesis warns. “I don’t like people who are fat and puffy!” Professional-wrestling-style flips and pile-drivers ensue. Sadly, Elvis is defeated and becomes a zombie. Happily, this twist of fate leads to love, for in a nearby graveyard he meets Zombie Priscilla. “Hi. My name is Elvis. I think you are a cute zombie,” says Zombie Elvis.

Priscilla responds swiftly, “Thanks! Right back at you—you are also a pretty cute zombie!” Love follows its natural course and Zombie Priscilla accepts Zombie Elvis’s proposal of marriage. He presents her with a gift: “I made this casket for you so that you can always stay with me for all eternity in Graceland. The small window on the casket allows me to stare at your beautiful zombie face.”

With that bit of dialogue, the accent changes, and a simple play with an absurd plot becomes suddenly something new: art about disability, from within.

Marisa Bingham wrote a post-modern fairy tale entitled *People Falling in Love When You’re Married*. In it, Movie Star Anthony and Queen Margaret meet; Anthony comments on Margaret’s perfume and headband. They quickly bond over a shared enthusiasm: “I absolutely love safari animals! They are interesting to know and learn about.”

Unfortunately, the two lovers are attacked by a space alien. Fortunately, Anthony kills it. He proposes. Margaret accepts. They embark on a limo ride to Milwaukee to meet Anthony’s mother. Unfortunately, the alien’s powerful friend is a vengeful queen. Double unfortunately, that queen happens to be Margaret’s mother. A spell is cast. Now when Margaret looks at her beloved, she is

overcome with horror; she can’t see that he is truly a movie star; she only sees a monster. The stage directions are clear: “Her nose wrinkles and she bites her bottom lip in utter disgust. She lets out a loud EWWWWW as she looks at Anthony.” Anthony reacts: “But, Queen Margaret, I thought you loved me!” Fortunately, Anthony takes up scrapbooking, the power of which reunites them so they can live happily ever after.

It’s hard not to notice that both plays follow a similar line: visages transformed by the hands of strange fate to ugliness, but somehow, despite it all, treasured. These are silly plays, and yet utterly haunting in their primal cry for one very human desire: to be seen and loved.

“When Nik was little, people told us he would never read, never write, never talk—now he does all of those things,” says his mother, Judy Neiss. No one bothered to tell her Nik would never write one-act plays about zombies or star in a campy musical about segregation in 1960s Baltimore.

THESE ARE SILLY PLAYS, AND YET UTTERLY HAUNTING IN THEIR PRIMAL CRY FOR ONE VERY HUMAN DESIRE: TO BE SEEN AND LOVED.

REPLACE WITH “A PERSON WITH A COGNITIVE AND/OR PHYSICAL DISABILITY”

That’s because the idea that the mentally impaired and physically disabled can produce art is a recent one. Before 1975, it was considered impossible, or impractical, even to attempt literacy in the mentally impaired. Before 1975, the answer to the question of what’s the right place in the world for people like Neiss was: somewhere else, away from the rest of us. And before that, the answer was: the grave.

THE BLACK STORK

About 3 percent of babies are born with one birth defect or another, from cleft palate to the most common of all birth defects: Down syndrome. It seems to have been ever so. The first recorded instance of a baby born with an intellectual disability is found on the ancient Egyptian Ebers Papyrus, a medical record from 1550 BC. For most of human history, infanticide was seen as the appropriate response.

Anthropologist Joseph Birdsell estimates that in Neolithic times 15 percent of infants were killed because of disability or to avoid having to feed them. The Greek historian Plutarch reported that Spartans convened panels of wise men to decide

which disabilities were severe enough that the infants should be abandoned out of doors. Plato and Aristotle held planned infanticide to be reasonable state policy. The Romans agreed. Then came biblical times.

The “Rules for Priests” section of Leviticus (21:18-22) states: “For the generations to come none of your descendants who has a defect may come near to offer the food of his God. No man who has any defect may come near: no man who is blind or lame, disfigured or deformed; no man with a crippled foot or hand, or who is a hunchback or a dwarf . . .” Even Protestant reformer Martin Luther said he saw the devil in a disabled child and advised killing the child. (This history haunts religion to this day; in the spring of 2012, an Italian priest barred a disabled boy from receiving communion, citing tradition.)

These anti-disability ideas were the norm for eons. Just a century ago, Chicago physician Dr. Harry J. Haiselden made a name for himself killing disabled babies. He claimed to have killed six babies himself, some by neglect and some by narcotic injections, and created a film to promote himself called *The Black Stork*. In 1915 he was put on trial for the death of one of those babies. The jury acquitted him. Remarkably, he received support from the most prominent disabled person of his day, Helen Keller, who noted “a human life is sacred only when it may be of some use to itself and to the world.”

As infanticide fell out of common practice, the question of what to do with the inevitable percentage of disabled children in every community became a complicated part of U.S. governance. Names we now take as sheer insult, “idiot,” “imbecile,” “moron,” and “feeble-minded,” were used by states to indicate levels of disability: Morons were smarter than idiots, for example. The Massachusetts Legislature’s 1846 census counted “361 idiots, exclusive of insane persons.” The document went on to note that these people “poison the whole moral atmosphere.” To prevent such poisoning, institutions were founded

(she looks at Anthony)

ANTHONY
But, Queen Margaret, I thought you loved me!

QUEEN MARGARET
Forget it. I could never love you.

ANTHONY
Margaret, you are the most beautiful woman in the world.

to confine the disabled and the insane, often together, sometimes in chains, sometimes in “crazy cellars.”

The true sea change in the Western world’s reaction to disability was, astoundingly, brought about by the Nazis, who killed somewhere between 100,000 and 250,000 disabled Aryans, young and old, many pulled straight from state care institutions. It was against this background that the American civil rights movement arose, and *Brown vs. Board of Education* anti-segregation decision was decided. What does that historic anti-segregation decision have to do with *Zombie Elvis*? Everything.

Neiss’s generation is the first to be, in education parlance, “mainstreamed.” Before 1975, most of the then 4 million disabled children in the United States were excluded from public schools. Inspired by *Brown vs. Board of Education* and the civil rights movement, parents mounted legal challenges to the separate-but-unequal



Zombie Elvis playwright Nik Neiss, in the hat, poses with friends.

education of the disabled. Two landmark cases, *Pennsylvania Association for Retarded Children (PARC)* vs. *Pennsylvania*, in 1971, and *Mills vs. Board of Education*, in 1972, drew on the equal protection guarantee of the 14th amendment as described in the deci-

sion of *Brown vs. Board of Education* to establish that children with disabilities had the right to free, appropriate public education in the least restrictive environment: ordinary schools. It was only this generation, the children with disabilities born around or after 1975, who began to be fully educated.

EXPECT THE UNEXPECTED

Neiss went to Dowling Elementary School in south Minneapolis. “Before Nik, [the disabled] weren’t even allowed to be in school,” remembers his mother. “It was such a difficult time. I just refused to sign the paperwork they kept giving us. I wanted him in a neighborhood school. I wanted him to be *included*. They wanted him in an institution. They wanted us to stop pushing. But that’s how he learned to read. I had to go to bat for him every day. I used to wake up in the middle of the night, my heart racing. I’d say, ‘Lord, it’s fine if you want me to do this, but send me the people I need.’ And he did.” People like Norm Munk.

Raised in New York, Munk came to Minnesota for his Edina-raised wife and for a job at the Wilder Foundation. He took over Partnership Resources, Inc. in 2000 with the vision of providing greater opportunity to people with disabilities. “The thing people fail to grasp is how many opportunities are denied to the disabled,” he says, as he checks in with people at the Minneapolis facility—men who communicate by sign-board and women with hands like a new bird’s wings, thin and folded in.

“Think about the opportunities, the expectations you present to your own child. You expect her to read—you provide everything to make it happen. If it doesn’t happen you **badger** and double down. And then, what a world that opens up for her!” Munk says. “But that’s not how society has traditionally approached the disabled. Children with disabilities were in the past raised without expectations.

“What many people fail to understand is that my clients—this could be any of us. We’re walking across the street—we get hit by a car. Or we’re sleeping in bed—we have a stroke. Now we have a traumatic brain injury. That’s where the idea for the art at PRI came from, in fact. My grandfather had a stroke. Everything was paralyzed on his right side. He couldn’t talk. He was despondent. My grandmother, who was the smartest woman, put a paintbrush in his left hand. He came back. He painted the most extraordinary pictures—beautiful



Marisa Bingham, with a few of her paintings, including a portrait of her mother (left).

landscapes of upstate New York.

“You could, tomorrow, find yourself in the exact situation many of my clients are in, as an extraordinarily high-functioning person trapped in a body that doesn’t function. Imagine! Last year I had back surgery—I was in the hospital just marveling at how lucky I am that I can talk, that I can express my needs. Imagine being in that situation and not being able to say this hurts, or this is alarming. I am always amazed we will spare no expense, do anything for a surgeon who has a car crash and finds himself trapped in a body that he suddenly can’t control, but if someone is born that way—we do not see them as worthy of the same effort.”

FOLLOW THE MONEY

Effort, of course, in society, is expressed in terms of dollars. Recent years have been brutal for social service agencies such as Munk’s because of state budget cuts and lack of increases in funding despite an increase in need. Minnesota has about 110,000 individuals on full medical disability under the age of 65, the result of birth defects, car crashes, strokes, and what have you. The state spends \$1.2 billion a year to care for them, and that number has been flat for a long time.

Munk says that his organization is about 20 percent behind inflation over the past seven years and hasn’t had a cost of living increase in five years. He makes up the gap through fundraising and entrepreneurship: Last year Target carried greeting cards featuring art created by his clients, which brought in several thousand dollars, and an annual fall benefit raises \$50,000. In addition, Munk has found support from private

foundations.

Steve Larson, the public policy director for The Arc of Minnesota, which advocates for the disabled, says it’s difficult to quantify exactly how state belt tightening has affected the disability community over the past decade, mainly because Minnesota has a highly individualized approach. Someone who needs help only in the mornings and evenings, for example, is allocated fewer dollars than someone who needs help around the clock; likewise, someone who can take a city bus is allocated fewer dollars than someone who needs specialized transport.

“The budget has held steady at \$1.2 billion,” Larson says. “There are about 4,000 people on a waiting list for services right now. These could be people waiting to live in a group home, waiting for employment supports, waiting for a PCA.” Personal care assistants, or PCAs, are a top concern right now because their wages have been reduced again and again since 2002. “We’re at something of a crisis, or at least a critical point in time,” Larson says. “If you want to keep qualified staff you have to eventually give them some raises, and we’re afraid that qualified people are leaving the profession, to be replaced with less qualified people.”

To deal with the shortfall, Larson says, the state is banking on legislative changes in 2013 dubbed MnChoices. Advocates say the changes would allow the state to spend money even more effectively by having, for example, a single staff member monitor a dozen or more disabled people via Skype, instead of in person, with

attendant technology to tell whether the stove is on, the water is running, and so on. Through the program, every Minnesotan receiving assistance for a disability will be individually assessed, evaluated using a single statewide standard, and allotted the minimum amount of care that will allow them to be maximally independent. Many worry that the decrease in funding will lead to the disabled returning to the easiest place to put them: out of sight.

SINGING AND PAINTING

Marisa Bingham is unaware of the financial battles waged on her behalf—battles that will determine everything from how long she and her peers are likely to live to whether anyone knows what they think. Or whether they can sing.

“Being in these plays opened up doors and elements of her personality that we never knew existed,” says Bingham’s mother, Julie St. Marie. “We had no idea she could sing. But I’ll tell you, she sings all the time now. She never sang before. And we didn’t know she could paint!”

St. Marie works at Best Buy. Her husband, Paul Bingham, quit his job to juggle their daughter’s frequent hospitalizations. “It gets to the point that you realize, one of us has to quit or both of us are going to get fired,” she says, shaking her head. St. Marie learned her daughter could paint when she arrived at a Partnership Resources gallery show and found a magnificent portrait—of herself.

“I was there,” remembers Munk. “Julie just broke down in tears of joy. It was one of the most moving moments in my life. Imagine having a daughter, and you’re always so busy keeping her alive that you never really get to think about whether she notices you, and one day there it is: She sees you and thinks you’re glorious. Those are the opportunities we create.”

Of course, opportunities bring new challenges, which bring new opportunities. Challenges like, now that Allison Baldrige has tasted the sweetness of stardom she wants more. “I believe in miracles, so I can move to Hollywood,” she says. “Though I hear Hollywood is a bad place to stay. I got a call from a guy in California. They’d pay me \$100, \$700, to act in Hollywood. But first I have to pay them \$280.”

She told him she’d get back to him and consulted the job coach who accompanies her during her shifts at Target to help her remember how to act and what’s expected.

“My job coach was like, ‘Allison, you’re being scammed!’”

Bingham’s mother worries about her getting scammed, too. Bingham isn’t allowed to go on Facebook unsupervised because she’s so trusting the family fears she’d give the first person who asked her social security number.

A VEIL LIFTED

People like Baldrige, Bingham, and Neiss are the very definition of vulnerable adults, and Minnesota’s disability advocates worry about the societal costs of not having adequate programming for them. The costs are high if they become victims of violence or crime, are financially or sexually exploited, or are unaware of basic medical issues like hydration that will lead them to the emergency room. Costs are also high for their families.

“Services are being more and more watered down,” says Munk. “Purely from an economic standpoint, for every family that has a disabled child and doesn’t get help, you’ve removed one if not two parents from the workforce—you’ve ended one or two careers.”

Munk believes reversing this trend is just a matter of raising “the veil of ignorance” about disabilities by encouraging the **severely disabled** not only to read but to **write, paint, sing, and dance**. As a byproduct, the rest of us are suddenly given a window into the inner lives of the disabled in a way that humanity never has experienced before. This veil-raising will continue with plays and, in the fall, a disability film festival for which Munk is currently seeking volunteers. “When we have this film festival, it is going to blow people’s minds,” he says. “We’ll have a red carpet for our clients.”

This makes Baldrige happy. Contemplating a red carpet, she ducks her chin and laughs. The fall is a bittersweet time for her. It’s her favorite season, but then it reminds her of when her grandma passed away. They were close. When she was little her grandparents called her the banana stealer. “Because whenever I’d go to their house I’d steal their bananas all the time and dip them in ketchup.”

Baldrige might include this detail of her life in the play she is working on, which will be autobiographical. “I want to act more,” she says. “There’s a huge hole in me. There’s something missing. The acting, singing, dancing—each time I’m on stage it fills that hole. It’s a great

feeling.” Remembering the feeling, she begins a smile, her pink cheeks rising. Then she buries her smile in her hands. “I think the thing that wouldn’t come out of me if I was just working, or just at home, is my smile. I have to fake-smile at work, because I have to be on. I have to pretend I’m happy when I’m not. But when I’m onstage that’s my real smile.”

With that, Baldrige lets her hands down and glimpses up, her real smile starting to peek out, and then she lifts her rosy cheeks and her eyes sparkle and her broad, real smile lights up the room. Her aide then helps her figure out how to put down her song sheet, helps her put on her coat, and gives her back the song sheet. These are the new lyrics she’s learning for her new play, which she has been laboring over for months. With that, she’s ready to board a little bus and go to play practice, where she’ll take her turn in the spotlight, on stage, a star. ■

REPLACE WITH “ALL INDIVIDUALS WITH DISABILITIES”

CHANGE TO “WRITE, PAINT, SING, DANCE, AND WORK. LIKE WE ALL DO”

USE PEOPLE FIRST LANGUAGE THROUGHOUT (SEE SIDEBAR NEXT PAGE).

REPLACE WITH “ENCOURAGE.”

EXAMPLES OF PEOPLE FIRST LANGUAGE

BY KATHIE SNOW; VISIT WWW.DISABILITYISNATURAL.COM TO SEE THE COMPLETE ARTICLE

Remember: a disability descriptor is simply a medical diagnosis.
People First Language respectfully puts the person before the disability.
A person with a disability is more *like* people without disabilities than different.

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
He has a cognitive disability/diagnosis.	He's mentally retarded.
She has autism (or a diagnosis of...).	She's autistic.
He has Down syndrome (or a diagnosis of...).	He's Down's; a mongoloid.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health condition/diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
He receives special ed services.	He's in special ed.
She has a developmental delay.	She's developmentally delayed.
Children without disabilities.	Normal or healthy kids.
Communicates with her eyes/device/etc.	Is non-verbal.
People we serve	Client, consumer, recipient, etc.
Congenital disability	Birth defect
Brain injury	Brain damaged
Accessible parking, hotel room, etc.	Handicapped parking, hotel room, etc.
She needs... or she uses...	She has problems with/has special needs.

Keep thinking—there are many other descriptors we need to change!

Excerpted from Kathie's People First Language article, available at www.disabilityisnatural.com.

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