

leading role in CODA, winner of this year's Academy Award for Best Picture, plus a personal Oscar for best actress for the 1986 film "Children of a Lesser God" make Marlee Matlin perhaps the nation's best known Jewish person with a disability. Her Jewish background, she has said, played a foundational role in her success in a profession that many people might consider an unlikely goal for a girl who lost her hearing at the age of 18 months. Beyond that, her recent prominence reflects a growing change—and continuing challenge—in the Jewish community.

Matlin's hearing parents joined an extraordinary Jewish congregation, Bene Shalom of Skokie, Illinois, where for decades deaf and hearing people have worshipped together through sign language and speech. It was revolutionary then for a group of deaf families and a recent rabbinical graduate, Douglas Goldhamer, to found a synagogue that defied not only long-standing customs and stereotypes, but a Talmudic proscription.

For the next 50 years, until his death in February, Rabbi Goldhamer helped open possibilities for countless deaf and hearing persons, and established a model of inclusive Judaism that defied stereotypes and practices long ingrained in Jewish tradition and American culture. He was one of the leaders

who, over recent decades, pioneered changes in how the Jewish community treats the 1 in 5 of its members—an estimate based on the typical rate in the United States, according to the Census Bureau—who have a disability.

"There have been some amazing strides," says Rabbi Julia Watts Belser, associate professor of Jewish Studies and core faculty in the Disability Studies Program at Georgetown University, who herself uses a wheelchair. In addition to practical efforts at inclusion, "we're seeing an increasing number of people teaching [and] working to develop more inclusive readings of Jewish texts." But, she adds, "It's also really important to continues thinking about understanding some of the ways in which exclusion or marginalization continues to happen."

## **Ending exclusion**

Leviticus 19:14 enjoins us not to "curse the deaf or put a stumbling block before the blind." But the deaf—one of three categories of people the Talmud exempts from the obligation to observe the mitzvot—were essentially excluded from Jewish worship, recalls Rabbi Shari Chen, professor of Hebrew language and executive director at Hebrew Seminary, the rabbinical school Goldhamer founded to train deaf and hearing rabbis to serve a wide range of Jewish communities.

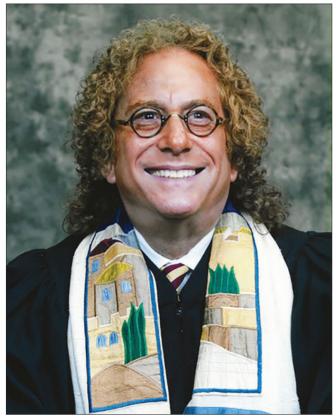


Photo credit: courtesy Bene Shalom, Skokie, III

For half a century, pioneer of inclusion and champion of the deaf Jewish community, Rabbi Douglas Goldhamer, (1945-2022), led the hearing-impaired congregation at Bene Shalom, a synagogue which he founded in Skokie, III. He also established a rabbinical seminary to train clergy to lead hearing-impaired worshippers.

"Because the deaf could not communicate" with the hearing in an ordinary way, they, along with those below the age of majority and those perceived as lacking mental acuity, had traditionally been "not welcome in temple," she says. She recalls a deaf Jewish family who, knowing they would not be welcome inside to worship, parked their car outside a Chicago synagogue on the High Holidays to be near the community at prayer.

In the early 1970s, Goldhamer, then a rabbinic student at Hebrew Union College in Cincinnati, first began visiting a group of Chicago Jewish families with deaf members and learning sign language. "I fell in love with the deaf community and fell out of love with the laws treating the deaf miserably," he told The Forward in 2021. After his ordination, Chen says, Goldhamer was told he couldn't serve the deaf, who in any case had no money to pay a rabbi. Undeterred, he went to live with families to cut expenses, meanwhile improving his sign language. In 1972, the group founded its own synagogue, choosing Bene Shalom as a spelling clearer to deaf people than



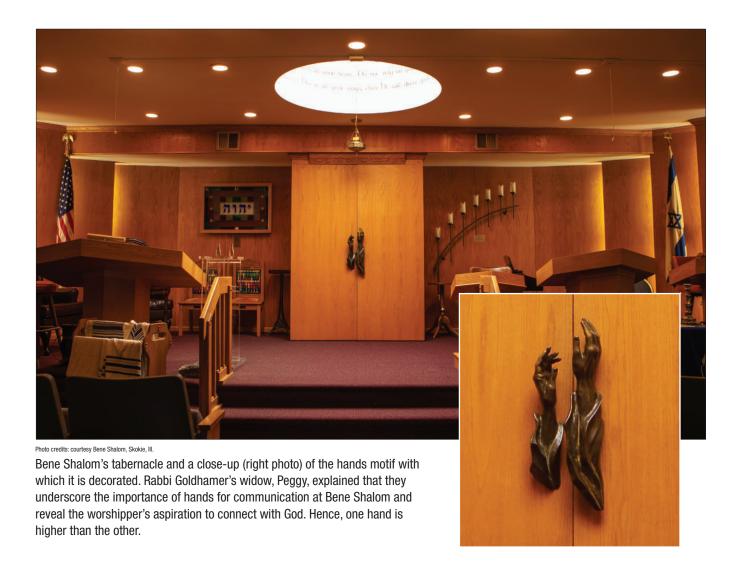
Photo credit: commons.wikipedia.org/State Farm

Oscar-winning actress Marlee Matlin, who has been deaf almost all her life, attended Congregation Bene Shalom with her parents and studied for her bat mitzvah with Rabbi Goldhamer. In a Chicago Sun-Times interview published this year, she remembered that he helped her learn "about my religious history, but more than that, really connecting [me] to my faith. Understanding that it was a very real part of who I am, beyond the Friday-night shabbat dinners and Hanukkah candles and presents."

the more traditional B'nai. All events and activities in both speech and sign were open to both deaf and hearing, and hearing people also began to join.

Matlin found in Bene Shalom "a community to belong to," she told The Forward in 2015. (She declined to be interviewed for this story). She attended services, met other deaf and hearing Jews, learned about her religion and celebrated her bat mitzvah like other young members. Achieving that always-challenging milestone, she said, "gave me the drive, it gave me the foundation to believe in myself, despite what other people say."

Having worked "frenetically" with Goldhamer to prepare, she told JewishBoston in 2017, she spoke Hebrew aloud and delivered the English in sign language interpreted orally for non-signers. Catching sight of her family's tears of joy and pride brought tears to her own eyes, but she saw that "my tears stained the Torah, and I was mortified." Goldhamer, though, noted that tears of both joy and sorrow fill Jewish history. "Many times, it was only the stain of tears that allowed us to



remember and to never forget and to continue," he said, as reported in The Forward. Matlin's "tears of joy," thus, "represent [her] and [her] parents' dreams—accomplishments and achievements of a young girl who happens to be deaf [and] are a wonderful message of inclusion and voice."

## Growing change

Despite a long history of discriminatory attitudes, policies and laws focusing on persons with a variety of disabilities, the United States began to change in the last three decades of the 20th century. The Education for All Handicapped Children Act of 1975 and the Americans with Disabilities Act (ADA) of 1990 laid the initial legal groundwork for much broader inclusion of persons with disabilities in all aspects of life, and elements across the Jewish community also began to move with the times.

Decades later, all the branches of Judaism encourage the inclusion of people with all manner of disabilities in Jewish life. Denominational websites and organizations offer extensive

resources, activities and training to help make this possible. Other groups also provide such resources and fill many specialized needs across the Jewish community.

But these steps in no way imply that the goal of full inclusion is near. The ADA, passed more than 30 years ago, exempted religious and related organizations. "Thus," says RespectAbility, a nonprofit that advocates for systemic change, "many such organizations do not yet have the attitudes, physical facilities or training they need to appropriately welcome people of all abilities." Only 24% of Jewish persons with disabilities who answered a survey that RespectAbility ran in 2021, for example, said that they believe the Jewish community is doing "extremely" or "very well" at including them in "synagogues, Jewish organizations and communal activities," while 40.7% answered "somewhat well" and 23%, "not so well" and "not at all well."

Though hardly impressive, these figures do represent some improvement over the results of a 2018 survey, when only 15.7% reported the community doing "extremely" or "very well"

but 22% answered "not so well" or "not at all well." Taking a longer view, 18.7% of the 2021 respondents with disabilities believed that "compared to 5 years ago," the Jewish community is "much better" at inclusion, though 39.6% said it is only "a little better." Meanwhile, 24.1% found the situation "about the same," with only 2% finding it "somewhat" or "much worse." Overall, persons without disabilities and those people involved in work concerning disability tended to view the situation somewhat more favorably than those with disabilities.

Founded by Jewish philanthropists to foster inclusion for individuals with disabilities from a wide range of backgrounds, RespectAbility has made helping religious organizations achieve inclusion one of its major program areas. Focusing initially on the Jewish community, it offers a range of resources and training on the practical issues involved in including persons with various disabilities in Jewish religious and community practices, customs and events—covering everything from synagogue services to service animals.

The fact that congregations, organizations and community institutions want and need such information indicates a growing consciousness of disability in Jewish life. We must "make sure that people with disabilities and those who love them belong, as part of the community, as valid and respected members," says Shelly Christensen, who became RespectAbility's senior director of Faith Inclusion in April.

The birth of a son with developmental disabilities first introduced the issue of inclusion to her. After years of struggle to obtain appropriate services from Minnesota public schools, she earned a graduate degree in developmental disabilities and worked professionally in the special education field. In 2002, she began attending annual meetings of the Jewish Special Education International Consortium, which brings together leaders in Jewish special education.

"In 2008," she recalls, "we discussed a way to collaborate on raising awareness, [deciding to] designate one month out of the year" for "a grassroots initiative, a community initiative, and we had enough members in different communities to serve as the central point people."

Studying the school and Jewish calendars, they chose February, a month with no major Jewish holidays. Those that do fall then, Purim and Tu B'Shvat, have messages "very applicable to disability awareness, inclusion, advocacy," she says. Purim teaches that "people wear masks. Their true selves are not necessarily what everyone sees when they see a person." In Tu B'Shvat "we're celebrating diversity, the diversity of nature, [that there's] ...not one way of being a person and we're all unique."

Christensen served as the initial central organizer of the first Jewish Disability, Awareness, Acceptance and Inclusion Month (JDAIM). From six communities the first year, 13 years later, "JDAIM is now recognized in synagogues, schools, youth programs and community and national/international organizations around the world," she writes in the 2022 edition of the JDAIM Program Guide. "JDAIM has elevated inclusion of people with disabilities and mental health conditions well beyond February. Many organizations have created formal structures to address inclusion concerns, hired professional staff and created lay committees."

## **Rethinking norms**

Fostering true inclusion requires thinking "explicitly about disability and disability experience as part and parcel of the very fabric of our communities," not as welcoming marginalized people to join "us," but as envisioning people in many community roles, including leadership, says Belser. But, she emphasizes, actually accomplishing this is complicated and challenging.

Customary—and often unnoticed—ways of doing things, she notes, can often unintentionally make some individuals feel excluded or even actually be excluded. Communities need to examine and rethink norms to try to prevent this.

For example, how do we lay out the spaces where we gather for prayer, ceremonies, socializing and learning? How does that affect how people can move and relate and function? What about the pace at which we do things, and what does that mean to people who require more time?

What are the expectations we hold for people in leadership positions, which, Belser says, often assumes that a person should "be able to give and give and give some more and then do another late-night meeting?" What does that say about persons who could be valuable leaders but lack such energy?

Belser continues, "the second thing is thinking about bringing people in, or allowing people to find their way in, or making it possible for people to find their way in who might not previously have been considered in the central group."

"Belonging is the heart of inclusion," Christensen says, "And the only way to really know what gives a person a sense of belonging is to ask." Placing the individual's desires at the center, she says, represents "a huge change" from the notion of, say, "running a special program for Sukkot so that they can visit the sukkah undisturbed." The huge challenge lying before the community is that each person be "not a mitzvah project, but a human being, being seen."