



The right to independent living in the community

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Last month Idaho hosted the 2009 Special Olympics World Winter Games. On his visit to the event, US Vice President Joseph Biden announced the appointment of Kareem Dale as special assistant to the president for disability policy - a brand new post. "He is going to have absolutely direct access to the president," Biden said.

Once more, the disabled population of Israel saw progress grace the lives of the disabled elsewhere. Meanwhile, here, the barriers to their equality have barely budged.

Bizchut, the Israel Human Rights Center for People with Disabilities, is painfully aware of the disparity between this country's treatment of its disabled citizens and that of most other developed countries.

This month it launched a booklet designed to instigate change in a most neglected area of disabled rights: living accommodation for the severely disabled.

Entitled "Land of the Limited Possibilities: The Rights of People with Mental Disabilities," its opening line succinctly states the central message: "Every person with disabilities enjoys a moral, ethical and legal right to live in the community... yet the road of people with disabilities to community-based living is riddled with legal and public battles."

Written by Naama Lerner, Bizchut's director of community programs, the thorough booklet is intended for professionals, parents and laymen alike. Moreover, it does not shy from packing a few punches at the Ministry of Welfare and Social Services and at several institutions for the disabled.

Its 58 pages present an array of clinical studies, statistical findings, judicial rulings, legislation, an international treaty and anecdotal reports from Bizchut's staff visits to institutions. They all substantiate the premise that institutionalization is harmful, unjustified, unnecessary, illegal and anachronistic. The Canadian champion of independent living, Dr. Michael Bach, is quoted in the booklet saying: "Institutionalization obliterates every trace of dignity and independence." One chapter surveys the origins of the practice. The universal popularity of institutionalization, we learn, rested on principles that are considered outdated and wrong today.

UNTIL THE 18TH CENTURY, it was believed that people who were in any way different endangered mainstream society. The category included the ill; the mentally, physically and emotionally disabled; unwed mothers; the poor and abandoned. To protect the rest of society, they were banished to large and isolating walled structures.

The concept of treating those incarcerated in institutions arose during the first half of the 20th century. During the next 50 years the view that those treatments were best administered in institutions remained unchallenged.

It was not until the second half of the 20th century that the popularity of institutions began to wane.

The West began to recognize that care within the community is the ideal. During the last 50 years, most developed countries have been opening community-based residences and shutting down existing institutions.

Studies into the effects of transferring residents from institutions to housing in the community leave no doubt that the quality of life, the health, the behavioral issues, the decision-making abilities and the social skills of people with disabilities benefit from the change.

Among countries that have made the switch are Sweden, Norway, New Zealand, numerous states in the US including New Hampshire, Maine, Rhode Island, West Virginia, Vermont, New Mexico and more. Canada will join this list by 2010. Great Britain closed the last institution for the mentally disabled in 2005.

Inexplicably, Israel lags way behind the above countries.

TRUE, IN THE last 15 years the Knesset enacted legislation that protects the rights of the disabled. The Fundamental Law of the Individual's Dignity and Independence and the Equal Rights for People with Disabilities Law (1998) chart a path toward integration of the disabled in education, employment, accessibility and residence.

In addition, the Welfare Law (Care of the Retarded, 1969) was amended to mandate preference for community-based housing for the mentally disabled.

A legal gap remains, however: No law declares the specific right of every citizen to live within the community.

Yet Israel is a signatory to (though it has not yet ratified) the United Nations treaty on the rights of the disabled. That treaty declares unequivocally: "Signatories recognize the equal right of all people with disabilities to live within the community." Several Israeli judgments have been handed down in cases brought by neighbors opposed to community-based residences. In nearly all of them the judges declared that people with disabilities enjoy an inalienable right to live within the community. Those decisions also obligate mainstream society to enable the attainment of that goal.

Recently the High Court of Justice determined that only those with severe medical conditions or whose behavior constitutes a danger may be denied the option of community living.

And this month, Bizchut won a favorable interim ruling in a High Court action in which it joined with the parents of two disabled adolescents. The justices gave the Ministry of Welfare and Social Services 21 days to respond with a solution that meets the accommodation needs of the children. The option of institutionalization has already been rejected by the court.

HOWEVER, THESE LEGISLATIVE and judicial strides have not been reflected in the reality that confronts the country's disabled population. The now-discredited principles that reigned for three bleak centuries remain entrenched in the Israeli psyche.

Thus, the Ministry of Welfare and Social Services still assigns most cognitively disabled individuals to large institutions. To quote Bizchut: "Therein, their basic right to a life of honor and equality are trampled with a crude leg."

The numbers speak for themselves: In 1997, 5,700 Israelis with disabilities lived in institutions, compared with 1,000 living in community-based apartments. By 2007 little had changed: 6,668 were institutionalized while 2,000 lived in community apartments. Moreover, of the 165 apartments available today, only four accommodate people with severe - rather than mild or moderate - disabilities.

The ministry is not the only source of resistance to in-community living for the disabled. The public has frequently objected to such residences in their neighborhoods. However, as the booklet points out, the presence of people with disabilities can enlighten even the most narrow-minded. Once the

contested residences were opened, former objectors usually warmed to their new neighbors.

Sadly, these cogent arguments leave Israel's bureaucrats cold. Both the ministry and the administrators of the country's newest mega-institution, Aleh Negev, separately responded to Bizchut. Their statements, printed at the back of the booklet, reject all of its assertions.

They also play a puerile semantic game. The word "institution" is avoided. The ministry substitutes it with the neutral "residence," while Aleh Negev opts for the more grandiose "rehabilitation village."

The ministry maintained that only in a "residence" could a person with disabilities feel "free to do as he pleases without anybody looking at him as abnormal." Ironically, it is this isolationism, favored by the ministry, which ensures the survival of such reprehensible attitudes.

Aleh Negev responded to Bizchut's account of a shocking case of abuse of one of its residents. Despite credible documentation of the injuries as well as the fact that Aleh Negev itself investigated internally and dismissed several staff members, it wrote: "The data that you have presented is entirely incorrect."

The bureaucratic obduracy facing people with disabilities is evident from the above responses. Kudos to the staff of Bizchut who channeled enormous energy and resources in defense of a sector that sorely needs assistance in its fight for equal rights.

More than 600,000 Israeli citizens, over 10 percent of the population, have disabilities. They patiently await the arrival of full equality to these shores. Hopefully, Bizchut will hasten the realization of their dream.

The writer and her husband founded the Malki Foundation (www.kerenmalki.org) in their daughter's memory. It provides support for Israeli families of all faiths who care at home for a special-needs child.

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