

## Who are they and what do they want?

### *An essay on TASH*

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People often ask why we have TASH. Don't we have enough organizations? Is there really a need for a separate group of people to represent people with severe disabilities? Why are TASH people so ideological and demanding? Don't they realize they are running into windmills? Why don't we put our resources behind those with more potential?

We have TASH because in the late 1960s and early 1970s it was abundantly clear to a few parents and professionals that no other organization was addressing the ideological, research, financial, and programmatic rights and needs of people with severe disabilities; the most vulnerable, segregated, abused, neglected, and denied people in our society. The people who were quarantined in horrible institution wards; who were excluded and rejected from public schools by too many of the continuum tolerators; who were confined to segregated activity centers and workshops; and who were quarantined in nursing homes and other unnatural living environments that were certified as acceptable by the ruling professionals.

In the early days of TASH we often wondered, if professionals are going to devote their careers to people with severe intellectual disabilities; if mothers, fathers, brothers, and sisters are going to spend enormous energies and resources over long periods of time fighting for basic services; and if legislators are going to be pressured to pass much needed legislation and to secure extremely important tax dollars, what is it that we want?

Initially, we wanted a ramp, more speech or physical therapy, someone to clean a catheter, money for research, service delivery model development and personnel preparation, a summer school program, and other isolated components. It soon became obvious that we should want the highest possible quality of integrated life for 24 hours a day, 7 days a week, 365 days a year for people's lifetimes. We started to dream that persons with disabilities should have all their resources, longitudinal support, respect, dignity, legal protections, and other phenomena necessary to be the most that they can be, to experience a humane existence, and to make meaningful contributions to their communities in accordance with their abilities.

Specifically, we started to strive for the healthiest possible bodies; opportunities for all children to grow up with non-disabled friends, neighbors, brothers and sisters; a society in which all people live in decent, family-style homes; the resources and support necessary to perform real work in the real world; and access to the richness and variety of heterogeneous local communities, including becoming involved in the same recreation/leisure environments and activities utilized by non-disabled others. In short, we

wanted integration and the resources necessary to realize and enjoy it.

Conversely, we also realized we did not want aversive conditioning, denial of medical treatment, disabled-only schools, institutions, organ harvesting, workshops, enclaves, group homes, retarded camps, Special Olympics, and other manifestations of segregation and de facto inferiority.

If that was the dream, what was necessary to approximate realizations? Several factors were considered critical at the time and seem at least as important today. First, we needed a penetrating, thought-provoking, constantly evolving cluster of values that would show us where to go and guide our way, get us through the rough spots and keep us focused on our targets. Values transcend individuals. They must be abstract, ideal, and pure. They must be scrutinized and evaluated in relation to their real and potential effects on the lives of people with disabilities, not on the people who expound them. Values should be enthusiastically discarded when they are no longer healthy or helpful and we should demand more and better from their replacements.

Second, we realized that the individuals we were attempting to serve were the most difficult to teach, the most challenging to render autonomous, and the ones who needed extraordinary assistance and support to realize reasonable personal fulfillment. The extant intellectual wasteland was unacceptable. Thus, one of the more consuming and enduring activities of TASH was, and still is, to use all the energies and resources necessary to convince talented, productive, effective, committed, and ideologically sound young people to pursue a wide variety of careers serving individuals with severe disabilities.

TASH never has been, and hopefully never will be, an organization that exists for its members. We are not a trade union. We are not interested in a group life insurance policy, a deferred annuity program, a tax-avoiding getaway vacation attached to the conference, or any other divisive, diluting, or distracting irrelevance. We can get all the above and more elsewhere. TASH exists to help people with severe disabilities and their families live the best possible lives. All we do should be referenced against that quest and anything that interferes should be resisted and resented.

Third, we knew that if we operationalized the best possible services conceivable in 1970, they would be embarrassingly inadequate. Thus, while we should always revere and respect that past and those who created it, we realized that we had a moral obligation to relentlessly pursue a better future. This commitment to new and better values, concepts, and practices often pit professional against professional, pit family member against family member, and converted friends, and colleagues to enemies. It still does. Some said let them die; we said no. Some said harvest their organs; we said no. Some said lock them up; we said no. Some said shock, beat, squirt, and tie them; we said no. Some said activity; we said work. Some said custody; we said access.

Fourth, and perhaps most important, we knew that we needed to join those few parents who were outraged by professional acts of commission and omission; who truly believed their children deserved more; who had the courage, will, and tenacity to challenge existing authorities; and who had the intelligence and insight to see through the mush and get to the heart of what was good for their children.

TASH learned some important lessons from some of the many mothers and fathers who did not plan to have a child with severe disabilities, but did. They were told to send them away,

lock them up or accept what was. They did not. They devoted unbelievable amounts of energy, creativity, sweat, money, time, and love to the betterment of their children. In most instances, it was not their children who benefited from their efforts, but all those like them who followed. We all owe tremendous debts of gratitude, continuous expressions of appreciation, and unbounded respect to these relentless, fantastically effective and creative mothers and fathers.

Who were Burt Blatt, Bill Bricker, and Marc Gold? They were some of the great early professionals of TASH who made wonderful differences in the lives of people with severe disabilities. They were people of vision, intensity, intelligence, wit, commitment, and charm. They were some of the rare geniuses who guided us in the early days – who made us believe that all people could learn, that all people had the right to live in decent homes, that no one should be abused, and that inclusion is better than exclusion. We cannot call them anymore and we cannot see them at the conference, but their spirits still move us.

Who are Tom Gilhool, Dick Cohen, David Shaw, John MacIntosh, Reed Martin, Frank Laski, Stan Eichner, Bill Dussault, David Baker, Orville Endicott, and Harvey Savage? They are some of the many lawyers who have expended substantial proportions of their professional lives trying to ensure that one third of the government of the United States and a major portion of the government of Canada – the judicial system – work for the most legally denied. They made Pennsylvania stop excluding children from public schools and start closing its institutions. They convinced the courts of the United States and Canada that all means all and that a person with disabilities is not one-half, three-fifths, or seven-eighths of a citizen. It is hard to imagine where we would be without these tough, brilliant, and remarkably effective legal Don Quixotes.

Finally, if we have learned anything at all over the past 20 years, it is that there are some aspects of a person's life that we have no right to compromise. We cannot negotiate the size of an institution; no one should live in one. We cannot function on a committee to determine who does and who does not get medical treatment; everyone does. We cannot debate who should get an integrated education; all must. Just because we are overwhelmed, frustrated and at a loss for something to do, we cannot tolerate shocks, slaps, pinches, or any other obnoxious violation of dignity. Let the moderates, compromisers, and data worshippers go elsewhere. Let the people of TASH be value based, unbending, tough, aggressive, assertive, graceful, compassionate, and effective.

Have no doubt that the people, allies, values, and experiences of TASH have accomplished much over the past 20 years. Have no doubt that much more must and will be done. Twenty years from now cars will be safer, cancer and AIDS will be cured, racism and sexism will be in the past, acid rain will be conquered and, if we do our jobs, people with severe disabilities will live productive, safe, healthy, happy and integrated lives.

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