

Benhaven

Restraint and Seclusion Prevention Initiative

Benhaven was started as a day school in 1967 by a parent of a boy with autism. Over the years, Benhaven added:

- Residential services for both children and adults
- Employment supports for adolescents and adults
- Community-based supports for individuals and families
- Benhaven Learning Network, which provides technical assistance and consultation, primarily to public school systems.
- Benhaven Learning Network also operates a school, Benhaven Academy, and a counseling service, the Social Learning Center at Benhaven.

The Benhaven School serves about 40 students for twelve months per year.

Benhaven has two group homes (capacity up to six for each home) for children and adolescents. Benhaven had three such homes for many years but recently converted one home from serving people of school age to serving adults.

Benhaven has five group homes for adults. One home is for two people. Three homes are for four people. One home is for six people. The day and employment supports for the people who live in these homes are managed by the home staff. Benhaven also provides day and employment support for two adults who live in their own homes.

Benhaven has six “shared living” homes – one adult (each was formerly a group home resident) residing with a family.

Benhaven’s Individual and Family Support program currently provides community-based support to 60-70 individuals and their families. Most of these are children or adolescents who live with their families.

The Benhaven Learning Network is currently consulting with, providing technical assistance to, or managing classrooms in approximately 25 Connecticut public school districts.

The Benhaven Academy serves about 20 students for ten months per year.

Benhaven was started for, and still serves and supports, children, adolescents and adults with the severe form of autism.

Typical problems associated with this form of autism include: serious deficits in communication and social skills, cognitive impairment, repetitive behavior and resistance to change.

Serious behavior problems including self-injury and violent aggression, while not always present, are quite common.

For its first 20 years, Benhaven approached its work in large part on direction and control. While much good learning took place, the teaching/learning experience was often difficult and dangerous. There were many serious behavior problems and they didn't seem to improve over time.

In 1986, based upon significant dissatisfaction with generally poor improvement in problem behavior, we began a major effort to understand autism better and to learn to use best practices in the field

We put together a five-person training team that spent three solid weeks learning from nationally known experts in the field about best practices in helping people with autism. This team then gave three weeks of training to twelve members of Benhaven's staff who had program leadership roles in the organization.

This “learning project” became a several year period of cascading new knowledge to the rest of Benhaven’s workforce. Special focus was given to functional assessment of problem behavior and developing communication skills.

By 1988, everyone who needed one had an individual behavior support plan. Each plan had teaching strategies designed to, over time, help make problem behavior that had a clear function unnecessary. Each plan also had reactive strategies, with options for addressing problem behavior.

Most of the strategies were in a hierarchy; some plans included restraint. From this point on, restraint was used only in those situations that were dangerous, when other strategies had been unsuccessful, and when restraint was the safest alternative to use.

Over the next few years, data showed that many ecological factors present in environments in which people lived, went to school, and worked can contribute to harmful behavior. Many factors can contribute to positive behavior. This realization led to the development of “positive behavior support plans”. As much as possible, environments were modified to make life easier for the person rather than more difficult.

We realized that many of Benhaven's environments were inappropriate for what we were trying to do. By 1990, we used "Essential Person-Centered Lifestyle Planning" and related person-centered approaches to plan, carry out, evaluate, and improve our work.

We then began to take on the enormous task of restructuring the organization to better support the work. We also tackled the problem of unsuitable environments.

Benhaven's new (and current) mission is to create and support the conditions that enable people with the problems associated with autism to:

- Participate in community life
- Have productive control over their own lives
- Be gainfully employed
- Have meaningful relationships
- Enjoy their own happiness and personal satisfaction

By the year 2000, we had made significant strides in helping people enjoy a much improved quality of life. While reducing the use of restraint was not a general goal for this succession of projects, accomplishments in learning by people in the program, growth in Benhaven personnel learning to respect and “listen” to people (even those who can’t talk), and realization of goals that offered a much improved lifestyle, led to a major decrease in the use of restraint.

NINETEEN ADULTS

- In 2001, Benhaven dissolved Benhaven Employment Services and started the “Real Lives, Real People Project”. This project involved 19 people who lived in Benhaven homes. Its purpose was to help 19 people develop rewarding and fulfilling lives and then work on helping each of them keep improving their lifestyles.
- Eight of these adults came to Benhaven from state institutions or psychiatric hospitals.
- Ten had been residential students at Benhaven.
- One came to Benhaven directly from Behavior Research Institute (now known as the Judge Rothenberg Center). One of the people who grew up in a state institution also came to Benhaven directly from BRI.
- 17 males and two females.

- Four members of the group had verbal skills at a conversational level. The other 15 people have severe cognitive limitations. All have some means of expression of wants and needs, but most of that is at a very concrete level.
- Nine people had a long history, documented in their records, of aggression severe enough to cause injury to another person at least as frequently as once per month.
- Seven people had a long history of self-injury at least as frequently as once per month.
- As of 2001, eleven people had behavior support plans that included restraint. As of September 2013, four people have behavior support plans that include restraint.

- In 2001, ten of the eleven people with restraint in their plans were restrained a total of 872 times. The low end of the range for a person being restrained over the year was ten (two people). The high end of the range was 351 for the year – all for self-injury.
- In 2001, the other person with restraint in his plan was equipped with a belt with restraint cuffs. He was in and out of these mechanical restraints on an almost daily basis. He had a fade protocol. He also had a protocol for requesting the mechanical restraints when he thought he needed them.

19 Adults	2001	2013
# Restraint as part of BSP's	11	4
Aggregate # restraints	872 + ongoing mechanical restraint	30 (mechanical restraint no longer used)

- During the period September 2012 through August 2013, the eleven people who had restraint protocols were restrained a total of 30 times (compared with 872 times in 2001). Two types of restraint were in the protocols. One is arm restraint (holding arms as gently as possible, but sufficiently firm) while using calming strategies. 19 of the 30 restraints during the year were of this type. Floor-control supine (with more than one person – but as few as necessary) were used 11 times, again while calming strategies are being used. One person was in floor restraint nine times; another person twice over the year.

There are a number of factors that have contributed to the achievements of these nineteen people:

- We committed to treating people with respect, courtesy, and gentleness.
- We made sure that people were receiving support from people whom they like and who liked them.
- We had smart, experienced people helping the people who provide direct support to be inspired to do great work to help others lead happy and useful lives.
- We were willing to take some risks to create home environments that worked for rather than against people and to develop opportunities in community settings where people, over time, welcomed, rather than resisted, people with “severe reputations”.

Learning to “listen” to people. It became pretty easy to grasp what people were communicating – at least indirectly. A few examples:

- “I really like going places with this person. That person – not so much.”
- “I think I’ve had enough of this job for a while.”
- “I’d much prefer to have a seated, indoor job.”
- “All the noise in this room is making me uncomfortable.”
- “When we get back to the house, I need a little time to adjust, so maybe I could hang out in my room for a while before we start to prepare dinner.”
- “I appreciate being able to be sure of what I’ll be doing over the next few days, because I get a bit anxious when I don’t.”
- “I really enjoy having things to look forward to, like parties, special events, and occasional vacations at a hotel where there is a hot tub.”

Larry Wood
Executive Director
Benhaven
187 Half Mile Road
North Haven, CT 06473
Phone: (203) 234-8454, ext. 301
E-mail: Lwood@Benhaven.org