DOJ Settlement Agreement: Implementation Perspective from the Community

July 18, 2013



To Be Addressed

- Brief Legend of Community/Training Center Downsizing
- SVTC Closure Experience and Strategies to Resolve Challenges
- Lessons Learned
- Considerations and regional issues
- Individual SVTC Transition Experiences
- Priorities to Assist the Settlement Process

Brief Legend

- Downsizing of Training Centers
 - 1980—3576 individuals
 - 2000—1694 individuals
 - 2012— (June) 969 individuals
 - 2013 (June), 790 individuals
- June, 2013, 9340 individuals reside in the community with ID Waiver slots
- July 1^{st,} 563 ID Waiver slots were allocated for those in most urgent need-Thank you!

Challenges Encountered-SVTC

- Community fear of group home concentration and burden on local resources, hospitals, transportation, etc.
- SVTC staff resistance to closure
- Parents and families' fears about change and closure
- Lack of enough "right fit" community providers
- Providers unprepared for accepted individuals

Challenges Encountered-Cont'd

- Massive adjustment in roles of all staff: SVTC, DBHDS, CSBs, Case Managers/Support Coordinators
- Rigid discharge plans developed by Training Center staff
- Adaptive equipment challenges
- Unclear initial guidance
- Complex discharge planning process
- Organizing the magnitude of the Settlement effort

- DBHDS, SVTC and CSB staff met continually to help SVTC staff learn about community options and possibilities for supports
- Trust built which assisted families as well
- CSBs took responsibility to find placements in home communities whenever possible, taking advantage of natural supports

- Regional meetings with potential providers to create understanding of individual needs and solutions in a community setting
- DBHDS held/continues provider forums to discuss issues, e.g., unique living arrangements possible to accommodate high medical needs
- CSBs worked with providers to develop medical practices, nursing support, assistance and necessary training of staff

- SVTC developed and provides "advance" training for providers prior to individuals being discharged
- Training includes enhanced protocols for physical management, specialized nutritional training, training by OTs for use of necessary equipment

- Discharge planning: CSBs brought PTs/OTs from community to work with SVTC staff on alternatives and equipment modification for community settings
- SVTC equipment transferred with the individual to the community placement
- CSBs supported willing providers to develop more expert capability to adjust their services and supports for the individual's needs

Lessons Learned/Evolving

- Everyone must want the safest and bestintegrated situation for each individual
- Plan with one individual at a time
- Know it takes time and it is tough going
- Trust among all parties must be developed
- Creativity about solutions with willing providers is vital
- Meetings and conversations taking place regularly-what is working or not, better alternatives and support within communities

Lessons Learned/Evolving

- Difficult conversations have to occur
- The additional CSB Case Management workload is daunting
- There can be no "gotchas". The goal must be working together to improve
- Gentle contacts must occur with families, despite reluctance, so that progress and new successes can be reported and seen by them
- Families who have agreed to transitions have become advocates for community placement

Vital Considerations

- Waiver re-design features in the works
- Adjustments to provider rates necessary
- Adjustments in Medicaid service to allow night coverage for emergency situations
- Continual clarification of roles and guidance
- Sharing Training Center resources with the community pro-actively
- Learning from families who have experienced transitions

Some regions may have a higher cost in developing capacity but it can be done

Regional Capacity Considerations

- NVTC: Provider rates for high cost area, housing development, pro-active sharing of TC resources, most residents from NOVA
- SWVTC: Geographic and transportation issues, distribution of medical and specialty providers
- CVTC: Residents from every region, only skilled nursing unit in a TC
- Capacity development of small ICF-nursing levels needed in each region

- E has been at SVTC since age 9 for major motor seizures, aggressive behaviors towards others, and self-injurious behaviors towards himself, which were hardest to prevent.
- Family had long been reluctant to consider transition, concerned about the long term financial stability of community.
- After years of reluctance, E's family saw the possibility of good placement and wanted rapid movement.

After 39 years in SVTC, at age 48, E is now living in his community, enjoying the company of a long time friend and attending a day program.

SVTC's behavior and medical protocols are supported in the community setting with a special facilitator and extra accommodation was made to prevent self-injurious behavior.

E's parents are very pleased with E's success in the community and take pleasure in his happiness with an active lifestyle.

- R, who is non-verbal, lived at SVTC for many years due to an extremely high level of medical needs including but not limited to:
- Constipation, severe GI issues and bleeding, Gtube feeding for all nutrition and medication
- ITP (affecting platelets), Spastic Quadriplegia, and Sinus Tachycardia resulting in mucus secretions needing regular suctioning by nurse
- Mobility dependence and repositioning needed every two hours to avoid skin breakdown

- Legal guardian open to community placement in home locality
- Nine providers identified but none could fully address R's issues
- Finally, a provider identified with skilled nursing, open floor plan in home for his large wheelchair, van transportation for day program
- Portable suctioning machine is used and transported with R each day

- R now serves as a greeter at his local church (his guardian too!) and approved to be usher
- Attends day program and engages in crafts, music, exercise, sensory stimulation, and social activities, including shopping
- Attending summer camp w/foreign students
- Loves to listen to <u>his</u> music in <u>his</u> home
- Guardian has observed how attuned his support partners are to his specific needs and is a champion for community.

Priorities to Assist Transitions

Funding for an RN with ID experience within each CSB to: (could be TC nurse transition opp.)

- Support families and individuals transitioning,
- Assist Case Managers in discharge planning for medical needs,
- Support providers in training and consults on medical needs,
- Support and consult with medical providers in the community regarding specialized medical conditions, appropriate medications, medication delivery.

Priorities to Assist Transitions

- Up to \$4000 per individual transitioning to community to assist with residential and personal items, day program specialized equipment, additional assessments for "right fit" services.
- Up to 6 months of Case Management allowed through the discharge process. Currently the work load and discharge requirements necessitate this additional time for many individuals.

Thank You!

Mary Ann Bergeron, Executive Director VACSB

mabergeron@vacsb.org
www.vacsb.org