

Comments of Peter Kinzler, NVTC Family Member of the SB 627 Work Group
On the Draft Factors, July 29, 2014

Attached are both a redline version of the draft factors circulated by DBHDS on July 17, 2014, and a clean version. Below is an explanation of my proposed changes.

1. My edits to the first factor revise it to incorporate the specific language of the Settlement Agreement (SA).
2. I propose adding a second factor, ensuring sufficient Training Center capacity for those who choose to remain in a Training Center. Coupled with the first factor, providing the necessary information for Center families to understand the key differences among their legal residential options under the ADA and the SA, the two provide the legal context for the actions of the Work Group. They are not really factors but statements of the law that apply 100% to all of the other factors.
3. I also propose adding a new factor, the number of people who wish to remain in a Training Center. This matter was discussed at the first meeting but not specifically memorialized in the draft factors. As the SA requires the State to provide sufficient Training Center capacity for those who desire to remain in a Center, I believe this is a key factor.
4. The rest of my proposed changes are edits to the DBHDS document. I propose moving the geographic proximity factor (old paragraph 6) up to a new number 4, as it relates directly to which Training Center people should be permitted to choose and thus, ultimately, to the task of the Work Group – to consider options for expanding the number of Training Centers that will remain open.
5. My new paragraph 5 combines old paragraphs 2 and 3, as both relate to quality of care. It revises the language to quote from the comparability of care language contained in SB 627. As a subset of this issue, I do not know what “sentinel event monitoring” means. Should it be “seminal events?”
6. My new paragraph 6 replaces old paragraph 4, which relates to the cost of providing care in the community versus a Training Center. It incorporates the concept that the proper comparison is between the cost of care in a “right-sized” Training Center versus the cost of *comparable* care in the community, as required by SB 627.
7. My new paragraph 7 focuses on maximizing the efficiency of any changes in order to minimize the financial impact on the State rather on the overall affordability, as the SA requires certain actions by the state, such as providing a number of slots for people on the waiting list and permitting the residents to remain in a Training Center, if they so choose.
8. My new paragraph 7 proposes narrow wordsmithing changes to DBHDS paragraph 7.

Draft List of Work Group's Factors

Each of these factors will be used to evaluate the options that may be recommended by the work group. Each factor provides a lens to examine the proposed options. The proposed factors have been worded to allow the workgroup to evaluate and raise questions that may require additional information or data to complete the assigned task of the workgroup.

Factors:

1. Ensure the State provides comprehensive information about the key differences between all legal residential options, including continued Training Center placement for residents, in a clear, objective manner to the Guardian/Resident/Authorized Representative/Family “[t]o prevent the unnecessary institutionalization of individuals with ID/DD and to provide them opportunities to live in the most integrated settings appropriate to their needs consistent with their informed choice . . .” Settlement Agreement, Sec. III (A) *Note: Assumption is that all information and options are provided in accordance with the Department of Justice Settlement Agreement, specifically Section IV(B), Paragraphs 9, 10, 11 and 12 as well as Section XXXX (need specific reference) of the Americans with Disabilities Act.*
2. Ensure the State provides sufficient Training Center capacity for residents if they or their Authorized Representatives elect to continue to reside in a State-run Training Center (“[N]o resident of a Training Center shall be discharged from a Training Center to a setting other than a Training Center if he or his Authorized Representative chooses to continue receiving services in a Training Center.” Paragraph 10 of the Settlement Agreement). *Note: “Nothing in this part shall be construed to require an individual with a disability to accept an accommodation . . . which such individual chooses not to accept.” 28CFR35.130(e)(1) (1998), ADA regulations.*
3. The number of residents of Training Centers (or ARs, where authorized by law to act on their behalf) who wish to remain in a Training Center.
4. Maximize geographic proximity of individuals with ID, including those who elect to continue care in a Training Center, to their families and local communities in order to encourage community integration.
5. “Provide a quality of care that is comparable to that provided in the resident’s current training center regarding medical, health, developmental, and behavioral care and safety” in either “the receiving training center or community-based option.” *Note: Quoted language from SB 627. Assumption that valid outcome measures, tracking indicators of all significant risks, and risk thresholds [“sentinel event monitoring”??] are in place as partial assurance that the individual continues to receive comparable care.*
6. The cost of serving individuals in a “right-sized” Training Center versus the cost of providing

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comparable care to such individuals in the community. If the costs of Training Center care would be more expensive, would the increased costs have a significant impact on access to services for those in the community? *Note: The cost comparison should reflect the full costs of the different settings. It should base Training Center costs on the assumption that the centers will be “right-sized” to reflect the lower populations. The community costs should include the costs of restructuring or building the needed capacity and the costs of any transitional effort needed to relocate residents.*

7. Maximize the efficiency of the changes in order to minimize the financial impact on the Commonwealth. Consider the best practices for siting, permitting, securing capital and financing capital improvements to existing Training Centers or other residential options in order to minimize the impact on current staff and financial resources.
8. Ensure that Training Centers provide the same type of livability that is available to individuals with ID or DD residing in the community, an environment that supports the individual as an individual and reinforces community collaborations typical of the non-disabled population.

Draft List of Workgroup's Factors

Each of these factors will be used to evaluate the options that may be recommended by the workgroup. Each factor provides a lens to examine the proposed options. The proposed factors have been worded to allow the workgroup to evaluate and raise questions that may require additional information or data to complete the assigned task of the workgroup.

Factors~~The Proposed Option:~~

1. ~~Ensures the State provides all appropriate comprehensive information is provided about the key differences between all legal options, including continued Training Center placement for residents, in a clear, objective manner~~ way to the Guardian/Resident/Authorized Representative/Family ~~“[t]o prevent the unnecessary institutionalization of individuals with ID/DD and to provide them with opportunities to live in—as to whether or not this is the most integrated settings that is appropriate to their needs consistent with their informed choice” for the individual available in order to make an informed decision as to most appropriate for meeting the individual's needs.~~ *Note: Assumption is that all information and options are provided in accordance with the Department of Justice Settlement Agreement, specifically Section IV, Paragraphs 9, 10, 11 and 12 as well as Section .XXXX (need specific reference) of the Americans with Disabilities Act.*
2. ~~Ensure the State provides sufficient Training Center capacity for residents if they or their Authorized Representatives elect to continue to reside in a State-run Training Center (“[N]o resident of a Training Center shall be discharged to a setting other than a Training Center if he or his Authorized Representative chooses to continue receiving services in a Training Center.” Paragraph 10 of the Settlement Agreement).~~ *Note: “Nothing in this part shall be construed to require an individual with a disability to accept an accommodation . . . which such individual chooses not to accept.” 28CFR35.130€(1) (1998), ADA regulations.*
3. ~~The number of residents of Training Center (or Authorized Representatives, where authorized by law to act on their behalf), who wish to remain in a Training Center.~~
4. ~~Maximize geographic proximity of individuals with ID and DD, including those who elect to continue care in a Training Center, to their families and local communities in order to encourage community integration.~~ *Note: Edited version of original paragraph 6.*
- 2.5. ~~“Provide a quality of care that is comparable to that provided in the resident’s current training center regarding medical, health, developmental, and behavioral care and safety” in either “the receiving training center or community-based option.” Provides for the individual's health, safety and quality of life which are maximized regardless of the individual's care setting.~~ *Note: Language quoted from SB 627. Assumption that valid outcome measures and "sentinel event monitoring" are in place and used to ensure the individual continues to receive appropriate*

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care.

- ~~3. Provides full and timely access to comparable and appropriate services and supports regardless of care setting or placement, including when transferring from one Training Center to another.~~
- ~~4.—~~
- ~~5.6. Increases, decreases or no impact on the current~~ The cost of serving individuals in a “right-sized” Training Center versus the cost of providing comparable care to such individuals~~those served~~ in the community, through the current ID or DD Waiver. And if the costs of Training Center care would be more expensive, would the increased costs have a significant impact on~~does this option potential impact~~ access to services for those in the community? Note: The cost comparison should reflect the full costs of the different settings. It should base Training Center costs on the assumption that the centers will be “right-sized” to reflect the lower populations. The community costs should include the costs of restructuring or building the needed capacity and the costs of any transitional effort needed to relocate residents.
- ~~6.7. Maximize the efficiency of the changes to minimize the financial~~ Impact on the Commonwealth, is either minimized or savings are realized, such that the overall affordability of the care system is maintained or improved rather than stressed. And, Consider the best practices for siting, -~~g processes of siting,~~ permitting, securing capital and financing capital improvements to existing Training Centers or other residential options in order to minimize the impact on- ~~do not tax~~ current staff and financial resources - impacting other priorities.
- ~~7. Increases, decreases or is neutral on impact to individuals and families who elect to continue care in a training center as within reasonable geographic proximity to both their families and the facility is integrated into the greater surrounding community providing access to the greater community similar to individuals who live in settings viewed as more integrated, due to size or location within neighborhoods.~~
- ~~8.—~~
- ~~9.8. Ensure the training centers p~~ Provides the same type of livability that is available to individuals with ID or DD residing in the community in an ~~for the non-disabled population and a qualitative~~ environment which supports the individual as an individual- and reinforces community collaborations typical of the non-disabled population.