

## Some key (*talking*) points about the *Benjamin* settlement agreement

### Replacement of the old settlement with a much better one.

**Q.** The Court approved an earlier settlement agreement in 2011 that many of the residents' families did not like. Is any part of that agreement still in effect?

A. No. The Court's approval of that agreement was overturned on appeal, and the 2011 agreement no longer has any legal effect. It has been replaced by the new agreement that the Court approved on September 25, 2014.

**Q.** Is there any chance that this new agreement will be overturned on appeal too?

A. No. All parties have signed on to the agreement and no one opposed it at the September 25, 2014 hearing. So there is no chance that anyone will take an appeal.

### The decision whether to stay in a State Center or move to a "community" facility.

**Q.** One of the main objections many of us had to the 2011 settlement was that if any State Center resident did not have a guardian or someone else who could object on his or her behalf, that resident was automatically placed on a "Planning List" for relocation to a "community" facility — even if the resident had lived in a State Center his or her entire life and considered it "home." Is that provision still a part of the new agreement?

A. No. There is nothing like that in the new agreement.

**Q.** Does this mean that anyone who currently lives in a State Center will automatically remain there?

A. Not necessarily. Under federal law, every resident of a State Center has a legal right to choose to continue to live in a State Center or to move to a "community" facility. The choice must be based on the individual's wishes and on what type of facility would be best for the individual. One of the main purposes of this settlement agreement is to set forth rules that make sure that a proper choice is made for each resident. There is no automatic default rule that says a resident will automatically stay in a State Center or will be moved. Instead, an individual decision will be made for each resident.

**Q.** Who makes that decision?

**A.** Here is how it works:

(1) If the resident has a guardian, the guardian makes the decision.

(2) If the resident does not have a guardian and is mentally and intellectually capable of making the decision for himself or herself, then the resident makes the decision. (It is very unlikely that any current residents of State Centers will have this capability because most have very severe levels of mental or intellectual disability.)

(3) If the resident does not have a guardian and is not capable of making the decision for himself or herself, the decision can be made by someone else on behalf of the resident (usually a family member) if that person is listed on the Personal Data Profile Sheet of the State Center as being the resident's "substitute decision-maker."

(4) If the resident has no guardian, is not capable of making his or her own decision, and has no substitute decision-maker, then the State Center's Facility Director makes the decision.

**Q.** Who is a guardian?

**A.** A guardian is someone appointed by a court to be a guardian of a resident, including anyone appointed by a court to be a successor to an original guardian. To be a guardian, you must have a court order appointing you.

**Q.** Suppose a resident who is incapable of deciding for himself or herself does not have a guardian, but he or she has family members who want to make decisions on the resident's behalf. Can that happen?

**A.** Yes, but the family members will have to be named as "substitute decision-makers." That just requires making sure that the State Center lists you on the resident's Personal Data Profile Sheet as a person authorized to make decisions on behalf of the resident. We have been assured that the State Centers do not usually object to requests by family members to be listed as substitute decision-makers, so you should not run into difficulty getting placed on the Data Profile Sheet. It would be better, however, to be appointed a guardian than to be listed as just a "substitute decision-maker" because a guardian has full legal rights to speak for the resident.

**Q.** Suppose a guardian or substitute decision-maker is not sure what choice to make. Will information be made available to help with the decision?

A. The State Centers will provide lists of organizations that can provide relevant information. Some of these will be pro-community organizations, like ARC, and some will be more neutral, like VOR. Each State Center's Relatives and Friends Association will be listed as a source of information. Those who wish to look into a particular facility will be provided with locations of online information about incident reports for each facility. There also will be quarterly reports about numbers of individuals who relocate and then are subject to founded incidents of abuse or neglect, so that that information can be considered as well.

**Q.** Suppose a guardian or substitute decision-maker decides that a resident should remain in a State Center and tells the State Center of that decision. Does the guardian or substitute decision-maker have to repeat that choice every year at the annual ISP meeting for it to remain effective?

A. No. You are to always have the ability to change a decision and that opportunity should be offered to you at least once a year. But if you decide that your decision is final and you don't want to be asked again, DPW is supposed to honor your request.

**Q.** You said that if the resident has no guardian or substitute-decision maker, then the Facility Director makes decisions for that resident. Doesn't that raise concerns that DPW will try to get the Facility Directors to place all of the residents for whom they make these decisions on the Planning List for relocation to "community" facilities, and thereby depopulate the State Centers?

A. This is one of the most difficult issues negotiated in the settlement. Every resident of a State Center has a right under federal law to choose to either continue living in a State Center or to move to a community facility, and someone has to be able to make that decision on behalf of a resident who has no one else to speak on the resident's behalf. The law provides that in such a situation, the Facility Director at the State Center acts as the resident's guardian and makes the decision. We couldn't take away that role of the Facility Directors, but we were able to set forth rules for how Facility Directors are to make these decisions. Here are some of the main rules:

(1) If appropriate, the Facility Director must meet with the resident and try to determine the resident's wishes.

(2) The Facility Director must review all of the resident’s records and consult with the resident’s Interdisciplinary Team, staff members who know the resident, and any family members or others who ask to be consulted.

(3) The Facility Director must determine whether the resident previously had a guardian or substitute decision-maker who expressed a preference about where the resident should live, and then must honor that preference unless there are such “significantly changed circumstances” (such as closure of a State Center) as to justify a departure from that stated preference. This means that if you are a guardian who expresses a desire for the resident to stay in a State Center and you then die without a successor guardian being appointed, then the Facility Director is still supposed to honor your wishes regarding the resident unless things have changed so much that your preference may no longer apply. If you want, you may provide the State Center with a written statement of the types of “changed circumstances” that you think would justify departing from your preference.

(4) The Facility Director must make an individualized determination of what is best for the resident based exclusively on the resident’s best interests, and may not base a decision on any general policy considerations of DPW, any budgetary or financial constraints, or any numerical quotas.

(5) The Facility Director must consider such things as the perceived preferences of the resident, whether the various options can provide the types of services and supports the individual needs (psychiatric, behavioral, medical, dental, nursing, etc.), and the availability of any services and supports that the individual would need be able to make a transition from a State Center to a community location.

(6) The Facility Director must make the decision in writing and explain the reasons for the decision. The decision then will be reviewed by a committee consisting of DPW’s Deputy Secretary of Developmental Programs, Executive Assistant of ODP, Director of the Bureau of Supports to People with Intellectual Disabilities, ODP Medical Director, and ODP Clinical Director to be sure that the Facility Director’s decision was made in compliance with the rules set forth in the agreement.

### **Protections for residents who wish to stay in a State Center.**

**Q.** Can a State Center resident be removed to a “community” facility if the resident or his or her guardian objects?

**A.** No. The Agreement protects a right of choice, and the choice of a guardian is to be honored. The agreement specifically states, “No Party will seek the removal of a class member from a state ICF/ID to a community placement.” The phrase

“No Party” includes DPW. A “class member” means every present resident of a State Center. A “state ICF/ID” means any of the five State Centers, including White Haven. So this sentence means that DPW will not seek to force an unwilling resident to move out of the State Center in which he or she now lives if the resident or his or her guardian does not want the resident to be moved.

**Q.** Does this mean that DPW has agreed never to close a State Center?

A. No. As a legal matter, DPW could not commit that it *never* will close a State Center in the future; DPW could not make an agreement today that will bind a Governor or Legislature about public policy decisions (such as keeping a State Center open) in the future. All DPW could say was that it has no *present* plan to close a State Center, and we made sure that DPW made that representation on the record in court at the time the settlement was approved on September 25, 2014. So the agreement means that DPW will not try to force an unwilling State Center resident to move out of a State Center so long as that State Center remains open. The agreement does not have anything to do with whether or not DPW will keep the State Centers open in the future.

**Q.** So how do we know that DPW will not try to circumvent this agreement by just closing State Centers?

A. DPW represented to the court that it has no *present* plans to close a State Center. It is possible that those plans can change at any time, and the fact that the current head of the Office of Development Programs (the office previously held by Fred Lokuta) is Steve Suroviec, who has made it clear that he would like to close State Centers, means that we all need to remain vigilant about this. Realistically, however, we all should understand that at some point, as the State Center populations age and the number of residents shrinks, some State Centers may have to close because it will make no economic sense to keep them open. This will be a political issue, and is not something we could address in this settlement agreement. Pay attention to what, if anything, the candidates for Governor say about this issue, talk to your legislators, and try to educate your neighbors, community leaders, and members of the press. For now, we have to assume that when DPW told us about its *present* plans it did so honestly and in good faith (we have no choice on that). But the agreement provides us with no protection from State Center closures in the future, other than to say that if DPW tries to close a State Center, we reserve our right to sue over that decision.

**Q.** The 2011 agreement provided that money allocated to the State Centers might be reallocated to “community” facilities. Does the new agreement still do that?

A. No. There is no provision like that in the new agreement, and the agreement states, “DPW will not use funds appropriated for state ICFs/ID to fund community services and supports” and “will not give funding of state ICFs/ID any lower priority in its budget requests than funding for community placements.”

**Procedures for moving to a “community” placement.**

**Q.** Does the settlement still provide for a “Planning List” containing names of those who will be relocated?

A. Yes, but the list will contain only those who made a choice to move (as determined by their guardians, etc.). The agreement states, “The Planning List will not include any class member who has not chosen or on whose behalf a choice was not made for community placement.”

**Q.** How many people will be moved?

A. All those who choose to move will be moved. If more than 50 choose to move, DPW has committed to move 50 residents each year (80 residents in the fiscal year ending June 30, 2014) until all those who choose to move have done so (it is logistically unrealistic to move higher numbers of residents in any one year). We have been told that DPW expects the total number of those who move to “community” facilities to be less than 200, but there are no limits and the number will be determined entirely by what individual choices are made.

**Q.** How long will residents be eligible to choose to move under the agreement?

A. The agreement will be in effect until June 30, 2018.

**Q.** How will DPW find appropriate community facilities for those who wish to move?

A. The agreement spells out a detailed procedure. Among the highlights:

(1) DPW will provide information about those seeking placement on a special website accessible by providers and DPW administrative entities that administer the community system.

(2) Once one or more providers express interest, more detailed discussions will be held with the provider(s) until a match is made.

(3) An ISP will be developed that will include a schedule for relocating the individual and that sets forth the community services and supports that are needed, including vocational programs, health care and nursing services, psychiatric and behavioral health services, assistive technology, and transitional services.

(4) If necessary, a Crisis Management Plan also will be developed to specify steps to be taken if there is a psychiatric or behavioral crisis that creates a risk of commitment to a psychiatric hospital.

(5) A regional office of ODP will assume responsibility to assure that the necessary services and supports are provided.

**Q.** Suppose a person moves to a “community” facility and then decides that it was an incorrect decision. Can the person return to the State Center?

A. The individual can return within one year (or longer if the individual’s ISP team believes a longer period is needed). But because moving back and forth is seldom in the best interest of an individual in these circumstances, the agreement provides for a two-month cure period during which measures first will be taken to try to resolve the issues that resulted in the dissatisfaction that caused the person to want to return. After one year, a person who wishes to return to a State Center might require a court order to do so.