

Testimony on Division of Developmental Disabilities “Path to Progress”
Assembly Human Services Committee
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Thank you for the opportunity to testify today on this important issue. I would first like to acknowledge Assemblyman Cryan and the other members of the Committee for holding this hearing and for your demonstrated commitment to individuals with developmental disabilities in New Jersey. I would also like to commend Acting Commissioner Jennifer Velez and Assistant Commissioner Kenneth Ritchey for their impressive work in drafting and submitting, in such a short time period, a final plan that includes significant improvements over the draft plan that the Division of Developmental Disabilities (“DDD”) released in March. For example, the final plan increases from 1005 to 1850 the number of individuals who will be transitioned out of institutions and into the community over the next eight years. Moreover, the pace of transition has increased, with the first 1000 persons being transitioned within four and a half years. We also commend DDD for committing to use the new Individualized Habilitation Plan (“IHP”)--a person-centered and strength-based assessment—in all institutions by September 2008. We were also encouraged by the increased attention that the Plan gives to needed behavioral supports for individuals transitioning to the community.

With that said, we do have several areas of concern about the plan and a number of questions that remain unanswered.

First, the Plan specifies that 582 individuals (approximately 20% of all institutional residents) have been deemed by staff to be inappropriate for community placement. In order for a person to be deemed eligible, they must have an “absence of behavior that poses a significant risk to self/others” and must not require a level of support that exceeds what can be provided in the community. We need to give this standard further study, and are doing so. Moreover, it is not clear from the Plan exactly how DDD determined that each of these individuals posed a “significant risk” to self/others (e.g., was it number of incidents, severity of incidents, or temporal proximity of incidents) or why supports that can be provided in an institutional setting cannot be provided in the community. It would be helpful for DDD to provide further clarification concerning the criteria it used to determine ineligibility, as this information is critical to a meaningful review of the Plan.

Having visited and met with residents in both institutional and community-based settings, I am troubled by any vague assertion that an individual cannot be supported in the community. In fact, I have seen community residences serving people with the same or very similar support needs as those living in institutions. I have also seen first-hand the enhanced quality of life that can result for many individuals when they have the opportunity to live and participate in their communities.

The draft plan also stated that 154 individuals opposed placement in the community. The final plan, however, reveals that these 154 persons did not themselves choose to stay in an institution. Rather, an “informant” who “knew the person well felt that the individual would not want to move ... if given a choice” and made the decision for him/her. We would like more information on who the informants were, how they inferred what the person’s preference would be, and whether DDD made any independent attempt to discern or verify preference.

I also have a significant concern about the 1298 individuals identified in the plan who did not oppose community placement and whom institutional staff deemed eligible to live in the community, but whose parents or guardians objected to such placement. Under the Plan, there is capacity to move 845 of these persons into the community within eight years, but only if their parents/guardians eventually agree to placement. Giving parents and guardians what effectively amounts to a veto power over these decisions raises significant concerns about self-direction and individual’s civil rights. It would be very helpful to know how many of such persons had parents, as opposed to guardians, who opposed placement and whether those who had guardians were nevertheless able to express a preference about where to live. Notwithstanding this veto issue, this still leaves 453 persons otherwise eligible for community placement who will not be transitioned into the community until 2020-2021 or “as long as it takes.” This is well beyond the statutorily mandated eight year time period.

The Plan also states that until the Community Care Waiver is changed, DDD must use the IHP as the documented service plan for all persons living in the community, but that DDD will use the Essential Living Plan as the transition plan for persons moving into the community. DDD acknowledges that this disjoint between service plan and transition plan is not ideal. It would be helpful if DDD were to explain the efforts it has made to resolve this problem, when it expects the problem to be corrected, and, in the interim, how stakeholders can be assured that this disjoint will not result in inadequate supports for persons transitioning into the community.

Finally, the issues addressed in this Plan are closely tied to how DDD plans to accommodate; 1) the 15,000 children with developmental disabilities (44% of DDD’s current caseload) who will be entering the adult DD system over the next several years; 2) the adults who are currently living with aging parents and are on a waiting list for community placement; and 3) the estimated 340 emergency placements needed each year. However, the Plan does not address how these individuals’ needs will be met or how implementation of the plan will affect these groups. It would be helpful if DDD could explain more fully how it plans to accommodate these groups and the interrelationship among them. Similarly, the issue of admissions criteria is a critically important factor in this discussion. The Plan states that DDD will be reevaluating its admissions criteria with stakeholder input and will be adding due process procedures. While I am encouraged by DDD’s acknowledgment of the need to clarify this issue and ensure due process, more information is needed and we will be closely monitoring this issue.

Thank you again for your commitment to this critically important public policy issue and for the opportunity to testify before you today.