

# Section 1115 Demonstrations: NY People First

## Public Comments

Title	Description	Created At
OPWDD Section 1115 Comments:	<p data-bbox="418 247 914 279">Subject: OPWDD Section 1115 Comments</p> <p data-bbox="418 289 756 321">Dear Ladies and Gentlemen;</p> <p data-bbox="418 331 1317 720">As the parents of a 34 year old man with Developmental Disabilities, we have read several draft reports and attended two meetings on the subject with some optimism and allot of concerns. We all know about or have heard expert testimony as to what can go wrong in an institutional setting without the proper oversight and vigilance. While we do not have the same opinion as the person cited in the NY Times article, we do agree with the need for change. We agree with the recommendations for a 24-hour hotline to report abuse, barring convicted felons from being employed, better standards for training and recognizing abuse and stiffer penalties for severe/repeat offenders. We do urge caution to not over regulate or penalize, which can negatively affect the majority of good agencies.</p> <p data-bbox="418 730 1317 1150">We moved here from New Jersey in 1987 due to the complete lack of any acceptable public service available for our Son's disabilities. Ryan was diagnosed as Neurologically Impaired: Multiple Handicaps and was rejected from the Public School System. At age 5 he was sent by Taxi to a Center for Children with all sorts of different disabilities and problems. The staff were not trained or certified, only "babysitters" acting as a Day Care Service for the disabled. Ryan's disabilities became worse and worse and he was incorrectly diagnosed as Aphasic when he was merely mimicking other children in the program. We know first hand what can go wrong in institutional settings. Through our vigilance and oversight we learned of the poor conditions and knew it was time for us to leave and get Ryan out of there.</p> <p data-bbox="418 1161 1317 1476">When we moved to New York we were introduced to Wildwood Programs by the Niskayuna School System. Ryan was enrolled in their school program when he was 9 years old. His transformation was fantastic in the first year alone. His communications improved, he began to read and he became an all around happy boy. Ryan progressed through all phases of growing up in Wildwood and is now in the Residential Program. While he still has disabilities with fine motor coordination and speech, we know he is happy and will be well taken care of by the wonderful Direct Care Staff at Wildwood, even after we are gone.</p> <p data-bbox="418 1486 1317 1707">While Ryan was neglected and abused in New Jersey, he has only found the best of care in New York and Wildwood Programs. They are a Model Agency and have always used Best Practices in monitoring and correcting neglect and abuse. I am proud to be a Board Member for 10 years. The Quality Assurance and Compliance Program monitors everyone and keeps Management and Board Members appraised of any and all issues.</p> <p data-bbox="418 1717 1317 1917">We would respectfully caution you and our legislators from over regulation and penalties which might impact the good and caring people that work at agencies like Wildwood. We hear too often that they are leaving the field because they don't feel appreciated and are afraid of losing their reputation and credibility. It would be a shame for this change in funding to result in harming the many good Direct Care Agencies and Staff. For example, we are</p>	2012-05-27 13:35

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	<p>very against having video cameras in our son's room. He does not need it nor does he want this intrusion of his privacy.</p> <p>Major concerns from our perspective are the lack of evidence that managed care is a successful, cost effective approach for addressing the long term needs for support that the people like our son Ryan need. Managed care has really only been applied to health care issues; and the people like our son are not "ill" but rather need long term supports to help them learn, grow, and stay healthy, active and stable in their lives. Also what happens to people already receiving services when a new assessment tool is used, and especially when the state, which does not know these individuals as people, will be hiring and training a whole new work force to do these assessments. The people who know them best need to be part of that process. In addition, if everything we hear is true, the funding that will go into the waiver will be less than what is used to fund the current system of supports for people with DD, and at the same time, all wait lists will have to be eliminated, meaning more people will need to be served with less dollars. We cannot see how quality can be preserved. What will happen to people's relationships and sense of community when they are driven to specific providers of contracted services? Who will want to serve people with high needs for support/behavioral challenges/medically frailty under a managed care system that is incentivized toward less than 24/7 support? Will the more efficient and effective agencies receive a larger percentage of the funding than the bloated, ineffective and less compassionate agencies? There are a myriad of worries but the need to support and adequately compensate the people doing the work--is paramount.</p> <p>Sincerely, Peter &amp; Patricia Nickel</p>	
<p>Self-Directed services 1. There is a lack of consistency and clarity in NY State's description of self-directed services throughout both t</p>	<p>Self-Directed Services and Meaningful Work</p>	<p>2012-05-25 13:57</p>
<p>Southern Tier Independence Center's Response</p>	<p>STIC, Inc., an Independent Living Center in Binghamton, NY, serves people with developmental and mental disabilities in several counties, is the largest voluntary provider of OPWDD Service Coordination in the Broome DDSO, and provides other OPWDD-funded services to people of all ages. Here are our comments.</p> <p>5000 Characters Too Short</p> <p>OPWDD's proposal is complex. CMS can't get sufficient information to inform its decision from this website. We request an opportunity to submit detailed comments.</p> <p>Avoidance of Tighter CMS Definition of "Home and Community-Based"</p> <p>The People First Waiver won't be subject to CMS's new definition of "home and community based" for Medicaid 1915(c) and other programs, which would compel OPWDD to move more people to the most integrated</p>	<p>2012-05-15 08:20</p>

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	<p>settings much faster than the proposed waiver. OPWDD should be required to use the new definition for all non-ICF residential programs.</p> <p><b>Cross-Systems Service Coordination Inadequate</b></p> <p>This plan doesn't commit other NYS disability service agencies to cooperate with OPWDD. OPWDD plans to hold local DISCOs accountable for coordinating services across agencies. Neither service coordinators nor DISCOs can do this because they can't compel providers to work together. Without explicit Executive Branch commitment to require state agencies to minimize eligibility, regulatory, and procedural conflicts that keep people with dual developmental and mental disability diagnoses from being served, this problem can't be solved.</p> <p><b>Quality System Inadequate</b></p> <p>OPWDD says that greater use of integrated settings and self-direction and more reliance on consumer satisfaction are central themes of the new waiver, but its Quality Scale doesn't focus on them. The Scale shows that OPWDD will only require changes from providers that have serious problems with basic health, safety, and fiscal governance issues. Agencies that unnecessarily segregate people, or don't respect their wishes, will suffer no greater penalty than not being deemed "high quality" providers. We object to OPWDD's failure to comply with CMS's demand that OPWDD fire employees convicted of criminal abuse or neglect. Approval of this application should be denied until NY passes legislation establishing certain dismissal for workers guilty of crimes irrespective of collective bargaining agreements.</p> <p><b>Insufficient Detail on Institutional Settings</b></p> <p>OPWDD says it will keep about 300 people in institutional settings for temporary rehabilitation purposes. But OPWDD has always falsely claimed such settings are temporary. The application defines "temporary" as "3 years" and has no information on admission/discharge criteria or monitoring. OPWDD's claims should be subject to heightened scrutiny; it should be required to define "temporary" as 18 months, and to submit detailed admission and discharge criteria, and a monitoring plan to ensure that the facilities are used as a last resort and discharges are timely.</p> <p><b>DISCOs Providing Direct Services is a Conflict of Interest</b></p> <p>OPWDD says some pilot DISCOs will provide both care coordination and direct services to the same people. This irreducible conflict of interest will inevitably result in self-referrals. Many provider agencies that are expected to apply to be DISCOs self-refer regularly. Service recipients and family members often say they were never told by these agencies about available services from other providers. Exclusive self-referral is unethical, so agencies do it informally. There are no discoverable policies or paper trails, and no matter what "firewalls" OPWDD requires from DISCOs, they will continue to self-refer if allowed.</p> <p>OPWDD should prohibit DISCOs from providing both care coordination and direct services to the same person under any circumstances except lack of availability of another provider of a specified service in the same geographical region.</p> <p><b>State Employees Aren't Independent</b></p>	

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	<p>OPWDD claims it will offer “independent” enrollment brokers/advocates, but they are likely to be OPWDD employees in many cases. OPWDD plans to do needs assessments that it also claims will be “independent”. OPWDD has a vested interest in limiting spending; its employees will have a clear conflict of interest in making decisions regarding level of need for services, and can’t be expected to be independent advocates. OPWDD should be required to use third parties that are neither DISCOs, service providers, nor state employees to conduct needs assessments and serve as advocates.</p> <p>Insufficient Information for DISCO Applicants</p> <p>OPWDD doesn’t plan to provide information about required fiscal resources and capitated rates until after DISCO pilot applications are approved. Potential applicants can’t make informed decisions on whether to apply without this information. OPWDD should be required to make that information public before it issues Requests for Applications.</p> <p>Good Things</p> <p>We support the request to waive annual Level of Care determinations, and OPWDD’s goals and timetable to reduce reliance on sheltered work.</p>	