

Meet Aaron Underwood, Age 30

The best choice – not the only choice!



Our son, Aaron, was born 8 weeks prematurely in December, 1979. While he survived the birth, the life long effects from subarachnoid and pulmonary hemorrhages are devastating. A large portion of his brain was destroyed with the subarachnoid hemorrhage. Aaron is profoundly neurologically impaired to the point that mental retardation is not even an appropriate descriptor. His functional abilities are in the 2-3 month range. Seizures, respiratory insufficiency, frequent aspiration pneumonias, cortical blindness, spastic tetraplegia with ever increasing spasticity are just a few of the daily challenges for his caregivers. Aaron has no purposeful movement and does not reach for nor grasp objects. He will remain in the position he is placed until someone repositions him. He has no bowel or bladder control – undergarments will be required for the rest of his life. An incomplete swallow coupled with frequent aspirations necessitates a feeding tube for all nutrition and medications. He can, and has, choked on his own mucus, cutting off his airway. Aaron is non-mobile and when not in bed is positioned in a custom made wheelchair which accommodates the curvature of his body. Aaron is also non-verbal and cannot communicate his needs. Needs must be anticipated and proactively met. Aaron requires and receives intensive skilled nursing care 24/7 at Central Wisconsin Center (CWC); a Medicaid certified and funded ICF/MR.

It was our intention to provide Aaron's care forever. However, his medical needs outpaced our ability as parents to meet the daily challenges presented. Aaron had spent several weeks at Central Wisconsin Center on "respite" visits during which time he was evaluated for a possible extended care admission. He qualified! But we still were not ready to stop providing the day to day care. Physical, emotional, and mental exhaustion finally forced us to make what turned out to be the best decision for Aaron. In August, 1983 we requested that bed at CWC for Aaron.

We will never deny it was a difficult decision arrived at only after many prayers and tears. We did not seek extended care for Aaron at CWC because we didn't love him; we sought extended care at CWC because we did love him so much that we wanted to give him the best shot possible at a quality life. It was not simply the only choice – **it was the best choice.**

We visited frequently. Quite honestly, we really didn't think they could do a better job at caring for him than his own parents. We were wrong! He now had access to the very best therapies and medical care available – all under one roof.

CWC can be an overwhelming place for the first time visitor as it is a place filled with individuals with a wide variety of horrific disabilities. Some disabilities are the result of birth injuries, strokes, childhood illnesses, near drownings or asphyxiation. One must personally witness the loving care provided each resident to fully understand why families choose CWC. The residents are most assuredly not "hidden away" nor forgotten. Families visit often. An active recreation program brings a variety of volunteers and diversified programs into CWC and also takes residents off campus to a variety of integration experiences when health permits for each resident.

CWC has a very active medical short term care program where individuals in community based settings are evaluated and changes in medication or programming are established, dental care is provided or wheelchair adjustments made. Some of the individuals in short term care are CWC residents who have been transitioned from CWC and for a variety of reasons have needed to return to CWC for stabilization before returning to their home or being placed in a new setting.

CWC was the focus of a United States Department of Justice CRIPA investigation beginning in 1992 and finally closing in 2006. Parents were not allowed to be involved in the investigation or the subsequent settlement agreement. We were informed that it would not be “appropriate”. Our loved ones who are adjudicated incompetent were not allowed to have families represent them or speak for them during this long painful process. Neither residents nor parents had input into an original settlement agreement by which USDOJ set quotas for discharging residents – not based on need but on numbers.

We fear that the new focus of the United States Department of Justice, not only looking at how a facility can provide better care, but now questioning whether the residents even need to be there will bring the Justice Department back to CWC with yet another lawsuit in an attempt to close it once again.

“Least restrictive environment” and “most integrated setting” are meaningless terms for Aaron and his peers at CWC. He will always function at an infant level despite the best therapies which he has been provided with all these years. This is reality.

Aaron’s right to “live in the world” is not being denied. He is in a “community” that is appropriate for him. So-called advocates wish to dismantle and eliminate this infrastructure of

services that Aaron and his similarly situated peers depend on by **choice** and need. Destroying a system that works for him will do nothing to protect his “rights”.

Our choice of ICF/MR care is supported by the ***Olmstead*** decision as ***Olmstead*** supports choice:

Justice Kennedy noted in his concurring opinion, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.” 119 S. Ct. at 2191.

**“As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... ‘Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution’ [quoting VOR’s *Amici Curiae* brief].”
Id.**



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