Thank you members of the Health and Human services Committee for the opportunity to provide testimony to you today. My name is Jamie Ray-Leonetti and I am the Associate Director of Policy at the Institute on Disabilities at Temple University. We are Pennsylvania's University Center for Excellence in Developmental Disabilities (UCEDD) Education, Research and Service and we are a statewide program. We are one of a network of 67 programs throughout the nation that are funded by the Administration on Intellectual and Developmental Disabilities within the US Department of Health and Human Services to conduct training, service, technical assistance, research and dissemination activities on behalf of people with developmental disabilities in this Commonwealth. The Institute has been Pennsylvania's UCEDD since 1973.

Since 1999, the Institute on disabilities has collaborated with the PA Office of Developmental Programs (ODP) to conduct and analyze data from Independent Monitoring for Quality (IM4Q), a statewide initiative to assess the quality of life of people with intellectual disabilities and autism in PA. This initiative is part of a national effort called National Core Indictors, where 46 states participate. Through NCI state performance indicators have been developed and states measure their performance on these indicators.

In PA, data are collected from a representative sample of individuals living in a variety of settings including family homes; own homes, group homes (1-4, 5+), public intermediate care facilities for people with intellectual disabilities (ICF/IDD), private ICF/IDD and life sharing. The data are collected through interviews with individuals and families. Trained teams of individuals collect the interviews, each team including at least one person with a disability or family member. The data are collected by non-profit organizations who are free from conflicts of interest (meaning they do not provide waiver services). The Institute on Disabilities analyzes the data and reports issued for the statewide sample and for each of the 48 intellectual disability programs across the state as well as for the state centers.

As the most recent data show (2017-2018) people living in public ICFs were slightly more satisfied. However, with regard to Dignity, Respect and Rights, people in public ICFs experienced less dignity than any group other than private ICFs. The data are
more troubling with regard to choice and inclusion where the state ICFs scored significantly lower than any other group.

In addition to the data mentioned, contrary to popular belief, it is not the people with mild disabilities that are most likely to succeed in the community, but rather people with the most significant disabilities. As the Pennhurst study showed, there was no one for whom a community placement was not possible. As a corollary to that, I was once told that for every person living in an institution there is a similarly situated person living in a community program. I would like to add to that corollary by saying, for every person living in an institution, there is a similarly situated person living successfully in the community, and a similarly situated person living at home with their family.

With regard to data at the national level, according to the State of the States in Intellectual and Developmental Disabilities (Braddock et.al. 2015), the population of state institutions has decreased by 12.7% nationally and by 9.4% in PA. With four institutions still open, PA is in the top 50% of states with institutions. As of 2017, thirteen states and the District of Columbia (DC, NH, VT, RI, AK, NM, WV, HI, ME, MI, OR, ASL, MN and IN) have closed all of their public institutions. PA has not proven to be a leader in this area – far from it. We are barely keeping pace with the rest of the country. The annual cost of supporting a person in a state institution is $255,692 nationally, and $378,016 in PA.

It has been suggested that Polk and Whitehaven could be downsized and used for things such as respite. To that, I say ask the families, but not the families whose sons and daughters live in institutions. Ask the families who have kept their sons and daughters at home for 20, 30 40 and 50 years. On the other hand, ask the families of young children who are living at home, going to school with their brothers, sisters, and friends. I am sure that none of them would find a state center to be a suitable place for their relatives - even for a weekend!
This report shows 2018 data from the IM4Q dataset (n=5354) compared to data from the State Center sample (State ICF, n=148). There are 6 scales which represent sections of the survey: Satisfaction, Dignity, Not Afraid, Choice, Inclusion, Family Satisfaction. A higher score is better for each of the 6 scales. Seven residence types are compared in each chart: State ICF (148 individuals), Lifesharing (261), own home (262), relative’s home (1438), private ICF (368), community home with 1-4 individuals (2558), and community home with 5 or more individuals (208). Higher scores indicate that individuals are less afraid. There is very little variation among scores. State ICF had the highest score; community home 1-4 had the lowest score. Higher scores indicate higher family satisfaction. There is little variation among scores. State ICF had the highest family satisfaction score; own home and community home 1-4 had the lowest.

Higher scores indicate higher satisfaction. There is little variation among scores. State ICF had the highest satisfaction score; own home had the lowest.
Higher scores indicate that staff and the people they live with are nicer to the individual. There is little variation among scores. Lifesharing, relative’s home, and community home 5+ had the highest dignity scores; state ICF and private ICF had the lowest.
Higher scores indicate greater levels of choice making. There is much variation among scores. Own home had the highest choice score; private ICF and state ICF had the lowest.
Higher scores indicate greater levels of community participation. There is much variation among scores. Lifesharing and own home had the highest inclusion scores; state ICF and private ICF had the lowest.