

# Ohio Senate Finance Subcommittee on Health and Medicaid

Testimony of Neil Castilow, Interested Party, Father of I/DD Son

Am. Sub. H. B. 166  
As Passed by the House

May 14, 2019

Chairman Hackett, Vice Chairman Huffman, Ranking Minority Member Thomas and members of the Ohio Senate Finance Subcommittee on Health and Medicaid:

My name is Neil Castilow an Ohio resident from Perry Township, Stark County. I am the biological father of an adult son (Mark) with autism - ID severe who is non-verbal, with limited cognitive ability and minimal behaviors. He presently is supported by a HCBS (Home and Community Based Services) - DD waiver residing in a licensed, group home and participating in an adult day service program. He previously resided in an Ohio DC (developmental center) relocating in 2004 to his current location. I actively participate in my son's life and advocate for him and others at both the state and federal level, for his rights, dignity and funding.

My bio includes recently completing two terms as a member of DD Council, serving as chair of the Children and Health committee and participating on numerous subject-related committees and study groups for DODD and local county boards. I am retired having been employed in middle and senior management positions in the appliance and OEM automotive parts manufacturing fields. I appreciate the opportunity to testify before you today. My testimony is specific to DD budget initiatives included in the *Am. Sub. H. B. 166 As Passed by the House* with emphasis on topics associated to the intellectually and developmentally disabled (I/DD) Ohio citizens residing in the community, such as my son.

I support the Department of Developmental Disabilities executive budget and recognize with praise the \$220 million investment over the next two years including additional funding for targeted initiatives such as the workforce support DSP hourly rate increase, the Early Intervention initiatives including the final conclusive move of the program to the Department of Developmental Disabilities as the lead state agency.

Based on the *Am. Sub. H. B. 166 As Passed by the House* are my comments on specific topics identified by section number, page number and line numbers.

### DIRECT SUPPORT PROFESSIONAL RATE INCREASE

SECTION 261.220

Page 3144

Lines Nos. 96869 – 96888

The turnover rate for DSP employees (statewide approx. 55%+) has been at crisis levels in Ohio for more than a decade. The HPC (homemaker personal care) services DSP's provide for consumers, who lack the capability to perform them is **critical to their overall health and safety**. The employee turnover rates have been roadblocks for progress on numerous levels with the I/DD population in addition to causing unexpected hospitalizations due to neglect and oversight which have increased unplanned Medicaid costs.

I am grateful for and fully support the \$13.00/Hour proposed rate for DSP's providing HPC services. This rate will have more of an impact to both current and prospective employees than providing two increases a year apart as previously introduced. My concern is, there does not appear to be a mechanism in place that ensures a new rate of pay is received by the DSP employee providing the services but relies on the "good faith" of the provider to make that happen.

### ADULT DAY SUPPORT AND NONMEDICAL TRANSPORTATION SERVICES WORKGROUP

Section 261.230

Pages 3144 – 3146

Lines Nos. 96889 – 96939

In Ohio, approximately three in every ten I/DD individuals identify to a profile of non-verbal, limited cognitive ability, acuity level C, with some degree of behaviors. Many of these individuals live in the community on HCBS-DD waivers (either in-group homes, communities of choice, private homes or with relatives) and currently approximately 17,000 **attend adult day service programs**. For these citizens, the promise of the *1915(c) Home and Community-Based Services (HCBS) Waivers Final Rule (CMS 2249-F/2296-F)* is enhanced by obtaining and retaining basic services of CHOICE including adult day services and non-medical transportation.

Revised and publicly released in January 2014, the HCBS Final waiver rule and guidance was reviewed by a nationally renowned legal entity who found it to contain and create unconstitutional and non-ADA compliant CHOICE limitations that non-

disabled Medicaid recipients, living next door, **do not face**. The United States Congress has been asked to rectify the unconstitutional overreach and the Americans with Disabilities Act violations contained in the rule and guidance. Morally and constitutionally I/DD citizens should not be confronted by double standards to their participation in or selecting and retaining basic services of CHOICE. Preserving the individuals' CHOICE based on their disabilities and person-centered plan is imperative.

Both adult day services and non-medical transportation are partially funded by Ohio's county board support system through property tax levies approved by each county's voters combined with federal draw-down funds. These (40% local 60% federal on average) dollars help to support local county Medicaid reimbursement services.

The workgroup established in the *Am. Sub. H. B. 166 As Passed by the House* to advise the Department of Developmental Disabilities on the payment system for adult day services and non-medical transportation identifies 13 organizations/participants including "one parent advocate". **I believe this advocate should be** a parent of an individual currently supported by a HCBS, DD waiver living in the community who attends an adult day service program and utilizes non-medical transportation.

## OHIO'S STATE PROTECTION AND ADVOCACY SYSTEM

Section 5123.603      Page 1971      Lines Nos. 60675 – 60691

I concur with the intent and inclusion of this language in the proposed current budget. Providing oversight to this agency of state government is necessary.

## HCBS "COMMUNITY INTEGRATION" and OVERSIGHT

Not in current budget

The revision of the HCBS Final waiver rule and guidance changed in a transformational manner the model for I/DD individuals to live, work and play in the community. The revised rule requires states to interpret, implement and enforce the rule abiding with the **guidelines established by CMS**. "Community integration" a part of this model change mandates I/DD individuals' inclusion in community group activities in integrated settings such as restaurants, shopping centers, movie theaters

etc. Downsizing of public and private ICF's (intermediate care facilities) in Ohio during the past two decades has resulted in an increase in more involved disabled citizens living in community settings on HCBS waivers than previously. The challenge facing providers of complying with the community integration mandate is to have sufficiently trained staff to organize and carry out a successful outing in a safe and healthy manner.

The Provider Compliance Office of the Ohio Department of Developmental Disabilities confirmed that health and safety oversight for community integration is the responsibility of local county boards of DD utilizing tools (questionnaires) provided on the DODD website. In my opinion this type of oversight does not represent a "boots on the ground" preventative strategy to address potential problems in advance but instead appears to be an after the fact response. Moving forward, I see an urgent need to ensure this **oversight is a planned, formalized strategy** designed to assess and identify potential concerns in advance to avoid community integration train wrecks.

Thank you for this opportunity to present and your attention.

Regards,  
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