



# Imagine Different... Achieve Different!

WE BELIEVE ALL CHILDREN SHOULD GROW UP IN **FAMILIES**,  
AND WITH THE RIGHT SUPPORTS THIS CAN HAPPEN  
**FOR ALL CHILDREN** WITH DISABILITIES

## *Imagine Different Coalition Comments on Proposed Consolidation*

I submit these comments on behalf of the Imagine Different Coalition, a statewide group of parents, advocates, citizens, allies, and other professionals working towards a Commonwealth that proudly assures that each and every child living here grows up in a family home where they are loved and nurtured.

We understand that the Governor has proposed to consolidate Departments of Aging, Drug and Alcohol Programs, Health, and Human Services into the Department of Health and Human Services. This is an ideal opportunity to centralize the locus of responsibility so that all children with developmental disabilities receive programmatic oversight from one state office. Currently, this is not the case. At this point in time, Office of Developmental Disabilities has programmatic responsibility only for the subset of children with the developmental disabilities (DD) of intellectual disability (ID) and autism (ASD). There is no clear responsibility for other children with DD—children with disabilities such as cerebral palsy, muscular dystrophy, spina bifida, epilepsy, and traumatic brain injury—and children with long-term health needs who rely on technology such as ventilators and feeding tubes to sustain life. Just like children with ID and ASD, these other children receive most of their disability-related services through the Medical Assistance (MA) program. Just like children with ID and ASD, these other children and their families have needs that cannot be met through MA alone, such as home modifications, respite care and in some cases Life-Sharing. Yet unlike children with ID or ASD, no DHS office is responsible at a programmatic level for these other children, with the exception of children with autism, who have a programmatic office, but no access to needed services. They currently are not eligible for any of the Medicaid waivers that could meet those needs and that could help them to continue to live with their families.

Consider this: DRP has a teenage client with Muscular Dystrophy who cannot use her limbs and uses a motorized wheelchair. She lives in a row home with several steps leading up to the front door. This teenage girl has been unable to get in and out of her house with her wheelchair – her only form of independent mobility. Even to get to the doctor or to school, her father, who has a bad back, has to carry her. As a result, she has missed a great deal of school, and can have nothing like a typical teenage life. If she had ID, she could get a wheelchair lift through the P/FDS waiver. But DHS has taken the position that such lifts are not covered by MA. Without ID, she is simply stuck in her home.



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As a part of the Department of Health and Human Services consolidation, we suggest that you assure a single, central locus of responsibility for all children with DD – including those who do not have ID or ASD and address the need for community and family-based services that Medical Assistance does not. We suggest the Office of Developmental Programs as a logical and appropriate location for all children with developmental disabilities. If this is not possible, we ask that you identify another Office. As you consolidate, please consider the opportunity to locate responsibility for children with all developmental disabilities.

Sincerely,

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