



APRC Proposed Autism CARES Amendments – Talking Points

- **OUR COMMUNITY’S HISTORY:** In enacting the Combating Autism Act of 2006 (CAA), and reauthorizing these programs in 2011 and 2014, Congresses and Presidents of both parties declared autism a national public health priority. **More than a decade of trying.**
- **HOW WE’VE GROWN:** When the CAA was adopted, the CDC estimated autism prevalence at 1 in 250 American children. One decade later the Centers for Disease Control estimates prevalence has risen to 1 in 68. **Up 368%**
- **WE WEREN’T HIDING:** While parents have rightly generated greater awareness, it is absurd to argue that there were anywhere nearly as many severely affected Americans with autism in earlier years as there are today. **Large numbers of non-verbal, often self-injurious children, suffering pain from GI and other medical disorders, weren’t simply unnoticed in American society. Kids were hurting then, and they are hurting now.**
- **LIMITED MEDICAL TREATMENT ADVANCES:** Despite Congress’ intention for an appropriate federal response to autism, there have been no meaningful advances in prevention or treatment, and the basic medical needs of children with autism continue to go unaddressed, often including chronic pain. **Whole person health overlooked.**
- **TIME TO MOVE STATUS QUO:** In 2014, Congress failed to improve on past autism legislation, despite GAO findings that much of the significant tax payer investment under these statutes has been poorly spent. **More kids diagnosed and less spent per capita on answers for them.**
- **TIME TO MOVE IS NOW:** Reform of federal autism efforts, aimed at the most severely affected members of autism community cannot wait another five years. The Autism CARES Act in 2019 must do more to stem the tide of increased prevalence and to seek to help with both the suffering and the costs to the federal government which come with that tide. **Our 1 in 68 can’t wait.**
- **THE FOLLOWING TWO AMENDMENT PROPOSALS BY APRC:** Endorsed by former Senators Santorum and Dodd, the original Senate authors of the Combating Autism Act of 2006. **Bi-partisan, experienced support for reform.**
- **WORK SMARTER, NOT HARDER:** The NIH, despite a reasonably balanced and thoughtful Strategic Plan for Autism Research, has ignored its own plan with at least 600% overspending on genetic research while underfunding environmental causation research (already a lower priority in the plan) by at least half. **As in cancer research, while genetic science is important and may have long term clinical relevance, in the foreseeable future, identifying environmental triggers for autism (the equivalents of carcinogens) and finding ways to reduce exposures, could have far greater effects in improving the health of America’s children.**
- **PARADIGM SHIFT:** In HRSA, attention must be directed to help the nation’s medical establishment properly address the medical needs of persons with autism, needs going shockingly unmet today. **Ulcers and tooth abscesses should be treated by physicians, not psychologists or behavior specialists.**



MORE SPECIFICALLY, THE APRC AMENDMENTS TO THE AUTISM C.A.R.E.S. ACT AS INTRODUCED ARE:

- **RATIONALIZE NIH AUTISM RESEARCH SPENDING:** Require the NIH to follow the Strategic Plan for Autism Research and associated budgetary requirements.

- **REFORM HRSA ACTIVITIES:** Create a medical treatment, whole person care model for people with autism.
 - HRSA’s autism mission should be expanded to include creating and cultivating a medical model for autism management, ie, a special patient population standard of care.
 - Mission of HRSA autism activities should include: Research-focused on people with ASD who have developmental regressions and co-occurring conditions and are suffering pain and multi-symptom medical concerns.
 - The objective should be required to develop and appropriately train all relevant medical personnel with regard to a treatment lifecycle for the co- occurring and underlying medical conditions for those with autism, including, but not limited to, GI disease, immunological disease, neurological disorders and metabolic disorder.
 - A multidisciplinary medical management model should be developed to expand appropriately upon the existing psychiatric model for the diagnosis and management of persons with ASD.
 - Require HRSA to present to Congress ASD recommended medical treatment plans and screening tools, including standard emergency care practices regarding the co-occurring morbidities for those with ASD.