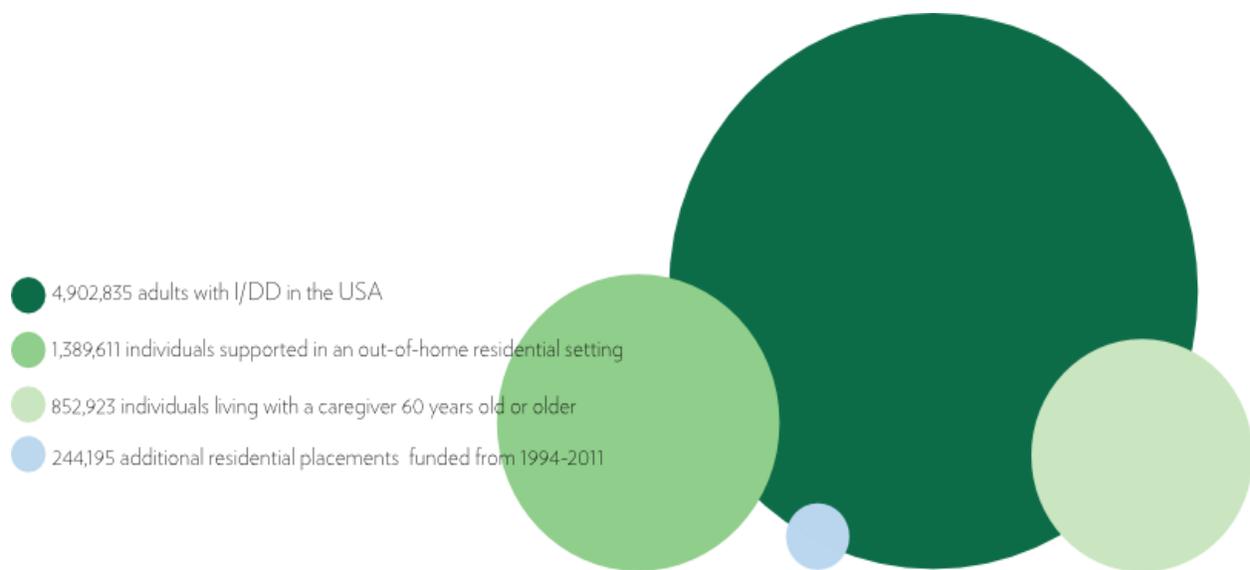


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To be presented at the April 2014 IACC Full Meeting
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Coalition for Community Choice (CCC) is a national grassroots collaboration of persons with disabilities, their families and friends, disability rights advocates, professionals, educators, and housing and services providers to advance the principle that community can be experienced in all residential settings. CCC was created to 1) promote and defend the rights of people with intellectual and developmental disabilities (I/DD) and autism to choose their residential settings from the broadest range of options; 2) educate federal and state governments on innovative Olmstead-compliant housing alternatives to “one-size fits all” approaches; and 3) preserve access to essential, publicly-funded services and supports in these settings.

Last week I visited a friend in Seattle who used to live in a group home. He met me at the park with a ziplock bag containing his meds because he has been living in a homeless shelter and was too embarrassed to tell me. He has tried desperately to find employment, but his vocal communication is somewhat incomprehensible. It is not easy to find a job when people do not believe you can communicate effectively.

I’m not a parent. I’m not autistic. But I have a lot of friends who are. The current and future demands for affordable housing and support service options are *overwhelming* the supply. Almost all states have waiting lists for accessing waiver funding, and opportunities that provide autism specific supports are few and far between. The growth of out-of-home placements in nearly 20 years for the entire population with developmental disabilities is both meager and unsustainable.



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013 (www.stateofthestates.org)

Michael John Carly, a self-advocate and witness at the last Congressional Hearing on Autism, testified that our greatest need is in the present and that autism is a national “service crisis”. In response, communities across the country are rolling up their sleeves to create local solutions. They know they cannot rely on government supports alone and there is no time to waste! We need more research into issues of adulthood; we need immediate housing and support service options; and we must eliminate barriers in policy and regulations for people trying to create public-private solutions.

Unfortunately, two barriers are making it difficult to proceed.

The first is:

Lack of research in autism specific supports for adults:

- a. How do setting design, program structure, and/or sensory friendly environments influence quality of life? Are these unique supports protected in policy?
- b. Those who have the most challenges are often the first denied opportunities. What are better supports for elopement? Self-injurious behavior? Or for those who become so frustrated that their only way to communicate is through physical expression? These individuals are most often isolated in their family home, being continuously excluded from their community. Where will they live when their parents can no longer be their primary caregiver?
- c. What trainings, assessments, and retention strategies are most effective for direct service staffing?

The second barrier is:

Restrictive public policy. Policy *must not* limit the opportunities for autistic adults to live self-determined lives. New HCBS regulations stigmatize farmsteads as an example of an “isolating setting” despite the fact that no research has been done on the quality of life for those who live in agricultural or intentional communities. Yet, for neurotypicals, the New York Times reported Agri-hoods are the newest housing trend, a residential development where a working farm is the central feature, in the same way that other communities may cluster around a golf course, pool or fitness center. Why shouldn’t autistic adults be able to use an HCBS waiver for a home and community of *their choice*?

Research is needed to answer the following questions:

- a. The housing and support options available for autistic adults in every state must be quantitatively and qualitatively assessed. How do they plan to meet the demand? Who is being left out or falling through the cracks? Are they meeting the needs and preferences of their constituents?

- b. What factors influence quality of life in private pay residential opportunities in comparison to publically funded options? Are they more financially sustainable?
- c. What incentives can influence the immediate increase of direct support staff and affordable housing opportunities to meet the needs of 1 million adults with a developmental disability who live with caregivers over the age of 60?

The Coalition for Community Choice is not a special interest group. We are a coalition of families, advocates and organizations willing to work together on real, meaningful, and self-directed solutions to give adults on the spectrum the future they want! Please advance both research and policy that decreases barriers and increases person-centered options. Thank you.