

Oral Public Comments

**IACC Full Committee
Meeting**

July 19, 2011

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Dan Burns

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Autism Trust USA Market Study Research Questions

Objective: What is the supply, demand, and future need for a residential/agricultural/vocational/wellness community specializing in autism?

Overview

What is our primary market area (PMA)? What is our secondary market area (SMA)?

Our primary market area (PMA) for the first model Autism Trust Center of Excellence is the Austin San Antonio Corridor. Our secondary market area (SMA) is the state of Texas.

What are the cities in our PMA?

The major cities are Georgetown, Round Rock, Austin, San Marcos, New Braunfels, and San Antonio. Smaller cities and towns include Taylor, Pflugerville, Elgin, Bastrop, Smithville, Lockhard, Luling, Seguin, and Floresville.

What are the counties and their populations (2010 census) in our PMA?

The counties are Bell (310,235), Williamson (422,679), Travis (1,024,266), Bastrop (74,171), Hays (157,107), Caldwell (38,066), Comal (108,472), Guadalupe (131,533), Bexar (1,714, 773) and Wilson (42,918)

What is the total population of our PMA?

The total population of our PMA (2010 Census) is a little over four million (4,024,220).

What is the population growth of our PMA?

Nine out of the ten counties in our PMA grew more than 25% in the 10 years from 2000 to 2010. Conservatively, we assume an additional 25% population growth from 2010 to 2020.

What is the prevalence of autism in our PMA?

Based on a 2006 cohort, the CDC estimates ASD prevalence to be 1 in 110 (nine-tenths of one percent, or .9%) nationally. This estimate is widely considered to be on the low side. For purposes of this study, we assume a prevalence of 1% in 2010.

How many individuals on the autism spectrum live in our PMA?

40,000 (four million times 1%)

How many of those have aged out of the entitlement system (21 or over)?

8,000 (20% of 40,000)

How many are under 21?

32,000 (80% of 40,000)

How are their ages distributed?

How many will age out of the entitlement system in 2011?

(32,000/21)

What is the rate of increase (or decrease) in prevalence?

According to the June 2011 issue of Pediatrics, in the 12-year period from 1997 to 2008, the prevalence of diagnosed ASD quadrupled (400% increase in 12 years). That is an increase of 13% per year. For purposes of this study, we assume an increase of diagnosed cases of autism of 10% per year for the next ten years.

How many families or households live in our PMA?

US census data pending.

How many families with at least one individual with an autism spectrum disorder (ASD) are in the primary market area now?

Pending.

How many are projected to be there in ten years?

Projections to be based on pending data.

How many are adults (21-64)?

Pending.

How many new adults will be added in ten years?

Pending.

How many individuals come from household with a parent or parents between the ages of 35 and 65?

Pending.

How many of those households have discretionary monthly incomes of at least \$3000?

Pending.

In addition, how many families receive or are waiting to receive income from the Medicaid Waiver Programs such as HCS?

Pending.

What is the average monthly HCS funding?

Pending.

How many individuals or households are receiving a monthly SSI payment?

Pending.

In Texas, will insurance pay the rent for residential housing for adults with autism?

Pending.

How many of those will want to live in a residential/agricultural/vocational/wellness community specializing in autism?

Pending.

How many residential units will it take to serve this population?

Pending.

Risks

What is the competition? That is, how many facilities specializing in the care of adults with autism exist in our PMA?

Pending.

What are the requirements for state-approved Home and Community-based residential settings or community living facilities?

Pending.

What certification or licensures are required?

Pending.

Sources:

<http://www.thecorridor.org/regions.html> (IACC Note: URL is not valid.)

<http://2010.census.gov/2010census/data/> (IACC Note: URL is not valid.)

<http://www.thecorridor.org/images/map-rail-sh130.jpg> (IACC Note: URL is not valid.)

[Dan Burns's presentation can be viewed here.](#) (PDF – 1 MB)

Note: Personally Identifiable Information (PII) has been redacted in this document

Jim Moody

July 19, 2011



IACC Members,

In our last statement to you, National Autism Association Board Chair Lori McIlwain discussed with you what our organization refers to as “Our Autism”. We represent thousands of families across the county who are in crisis on a daily basis.

A quick look through news headlines of just the last few weeks highlights the level of urgent need facing those affected by severe autism.

- Autistic Boy Dropped Off, Abandoned at Hospital
- Mother of abandoned boy with autism 'overwhelmed'
- Autistic teen killed by police
- Special Needs Kids Tied Down, Blindfolded On Bus
- Mother Killed Autistic Son with Coat Belt so "no one could point fingers at him" when he was in heaven
- Autistic Child Found Wandering Along I-17 Access Road
- Missing Indiana Boy Found Dead ([PII redacted], age 7)
- Parents Tell Tales of Restraint and Seclusion
- Young Portland man, 17, who has mental disabilities, missing since Tuesday
- Police Report: Missing Child Wanders Into Stranger's Home
- Naked child found alone at convenience store
- Teacher probed for hitting pupil
- Abbotsford dad devastated that autistic daughter is removed from home (following a wandering incident)
- Police ask for public's help in finding Autistic man
- Mother trying to build fence for autistic son
- Police hunt for missing schoolboy

Families are overwhelmed with the level of care required for their loved ones. For many, just keeping their child safe from potential harm caused by restraint, abuse, bullying and wandering is an exhausting, 24/7 job.

In addition to safety issues, many individuals with an autism diagnosis suffer from debilitating health issues including painful, chronic gastrointestinal issues, seizures, sleep disorders, self-injurious behaviors, aggression, paralyzing anxiety, crippling OCD and more. Families are struggling under the weight of incredible stress with little, if any, respite, effective treatment options or financial assistance.

Adults and teenagers rapidly aging out of our school systems face a lack of appropriate support, services, employment opportunities and supported living arrangements.

With one percent of America's children being diagnosed with an autism spectrum disorder, **we stand in the midst of a national health emergency** – a crisis deserving the utmost attention, resources and urgency that we can summon.

While the IACC strives to address the autism epidemic as best it can with the resources provided, it is simply nowhere near enough. You do not have the man-power or the funding necessary to effectively meet the many diverse and significant needs of this community that require and deserve around-the-clock attention.

Among the major issues that need urgent action are:

- Prevention
- Medical Care
- Residential Services & Support
- Insurance Coverage for medical care, therapies and safety equipment
- Employment Training & Support for adults
- Targeted, meaningful research aimed at prevention and treatment
- Safety issues including Wandering, Bullying, Restraint, Seclusion and Abuse
- Higher Education for individuals with ASD
- Training, education and support for caregivers
- Training for first responders and law enforcement personnel

As an advisory committee you are tasked with making recommendations to our government. We ask that you consider the recommendation of a presidential task force on autism. As committee members, you come together a few times a year and then go back to your day jobs. This is not nearly enough to address the widespread needs of our community. We need a dedicated, full-time task force consisting of a team of experts and stakeholders who are responsible for thoroughly addressing each of the crucial areas of need for this community. We need a team dedicated solely to this epidemic that now affects hundreds of thousands of families across the country.

A task force is needed to:

- Identify the full scope of needs of individuals affected by autism and their families
- Be an effective liaison between the autism community and government
- Conduct oversight of all federal research funding, encouraging “need to know” rather than “nice to know” spending to find the answers we so desperately need as quickly as possible
- Develop a 20 year strategic plan to thoroughly address and put an end to the epidemic
- Draft, advocate for, and guide relevant autism-related legislation
- Oversee, integrate and streamline autism-related efforts of all federal agencies to avoid overlap, duplication of efforts and wasteful spending

Government representatives, scientists, researchers and clinicians are simply not aware of, or in touch with, the real-life issues that families face every day. Therefore, this task force should include significant representation of community stakeholders knowledgeable on each area of need, allowing it to be driven forward by the sense of urgency that only stakeholders can provide.

On behalf of our families and those that we serve, we ask for your serious consideration of this recommendation.

National Autism Association
Wendy Fournier, President