Opportunity & Innovation in the Autism Market-
The Beacon Health Options Strategy

OPEN MINDS Strategy and Innovation Institute

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June 3, 2019
James Craig, LCSW, MBA is the Corporate Vice President for Autism Solutions at Beacon Health Options, the largest autism services managed care provider in the US with over 14,000 cases in service covering over 14 million lives. In this role, he is responsible for Beacon’s product strategy and the ongoing development and continuous improvement of clinical services delivered to children diagnosed with autism spectrum disorder and their families and supports the Beacon autism clinical teams throughout the United States.

James has held numerous positions in managed behavioral healthcare most recently as the Director of Behavioral Operations at Accolade, a start-up concierge company specializing in integrated approaches to support medical and behavioral health decision making for consumers. Prior to that, he served as General Manager for Behavioral Health at Aetna for the Eastern United States where he was responsible for health plans and self-insured customers. In this capacity, James developed the first Autism Case Management program incorporating a care coordination and utilization management model in fulfilment of the emerging state mandates.

James has developed a wide range of behavioral health programs designed to improve quality and effectiveness that have led to behavior change for those with medical and behavioral health issues. These have included telehealth coaching, online social media resources and member and provider engagement strategies.
Beacon has a 30-year history providing managed behavioral health care services

- Headquartered in Boston; more than 70 US locations
- 4,700 employees serving 40 million people across the country
- 180 Employer clients; 41 Fortune 500 companies
- Partnerships with 65 health plans
- Programs serving Medicaid recipients in 24 states and the District of Columbia
- Serving 5.4 million military personnel and their families
- Autism: 14,000 cases in care serving 14 million lives
Beacon’s Medicaid programs include health plan partnerships and direct-to-state contracts.

We implemented new Medi-Cal autism benefits on behalf of 6 Medicaid plan partners.

Beacon has managed the country’s first statewide Medicaid carve-out since 1996 serving 450K children and adults.

14 Million Members w/ ABA benefits
### Stakeholders’ Needs

<table>
<thead>
<tr>
<th>Member Engagement</th>
<th>Provider Engagement</th>
<th>Plan Engagement</th>
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<tbody>
<tr>
<td>• Prompt access to providers</td>
<td>• Claims paid promptly, correctly</td>
<td>• Understand added value of Beacon’s services</td>
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<tr>
<td>• Assistance with referrals, benefits, advocacy,</td>
<td>• Understand documentation rules</td>
<td>• Take care of their families</td>
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<tr>
<td>community supports</td>
<td>• Incorporate their data more effectively</td>
<td>• Access → cost</td>
</tr>
<tr>
<td>• Assurance of continuity of care</td>
<td>• More efficient treatment models to address costs</td>
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What is Autism Spectrum Disorder?

- The CDC reports a prevalence rate of 1:59
- ASD can be diagnosed as early as two years of age but the median age of diagnosis is three years and 10 months
- Common symptoms include:
  - Repetitive behavior
  - Lack of eye contact
  - Delayed language learning
  - Poor motor skills
  - Sensory sensitivities

Applied Behavioral Analysis (ABA) Therapy

- ABA is the most accepted treatment for Autism
- Assessment and treatment planning is done by a Board Certified Behavioral Analyst (BCBA)
- Applies interventions that enforce socially significant behaviors and discourage maladaptive behaviors
- Trains child and parents simultaneously to modify behaviors and skills, ultimately with the parent becoming ABA experts
- Historically in-home, school, community
- New focus on development of center-based services

Level 1: “Requiring Support”
Verbal, functioning but have communication challenges

Level 2: “Requiring Substantial Support”
Non-verbal, severe deficits in social skills

Level 3: “Requiring Substantial Support”
Autism prevalence has been increasing and states are mandating coverage

- There are notable tailwinds driving demand
- Current national prevalence is ~1.7%
- 49 states mandate coverage of autism services, with many employers following suit largely due to parity concerns
- In 2014, CMS mandated every state to develop plans to not restrict autism benefits either through the state (contract with providers) or MCOs
- In 2017 the Federal Employee Health Benefit directed its carriers to no longer exclude coverage of ABA
- 29 States + DC have included ABA as an Essential Health Benefit as part of the Affordable Care Act
- Expansion of large multi-state practices (CARD, Trumpet, Autism Learning Partners, etc.)

<table>
<thead>
<tr>
<th>Metric</th>
<th>Statistic</th>
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<tr>
<td>Population under 21</td>
<td>85 M</td>
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<tr>
<td>% Assumed to be Diagnosable with Autism</td>
<td>1.7% Range-.6 to 2.9%</td>
</tr>
<tr>
<td># of children Assumed to be Diagnosable with Autism</td>
<td>12.4 M</td>
</tr>
<tr>
<td>% of insured autistic pop with ABA coverage</td>
<td>70%</td>
</tr>
<tr>
<td>ABA penetration rate</td>
<td>Ranges from 8% to 17.5%</td>
</tr>
<tr>
<td># of insured Autistic children receiving ABA</td>
<td>98,815</td>
</tr>
<tr>
<td>Average # of hours of ABA / year</td>
<td>1300</td>
</tr>
<tr>
<td>ABA Autism Market</td>
<td>$7.6 to $70B (est)</td>
</tr>
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Access to developmental specialists

- **Shortage of pediatric subspecialties** that diagnoses and treat ASD
- Appointment wait times: At least **6-8 months** in many areas

- **Nationwide shortage of BCBAs**
  - Increased prevalence of ASD diagnosis: **49 states mandate coverage**
  - BCBAs not distributed **evenly**

- Factors unique to rural areas: **geographic distances** to providers, **low reliance** on health care professionals, **cultural characteristics**, **low socioeconomic** and **education levels**

- Median age for diagnosis: **3 years and 10 months**; ASD diagnosis can occur as early as 2
- Delayed diagnosis: **Loss of crucial time for early intervention**

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"US Behavior Analyst Workforce- Understanding the National Demand for Behavior Analysts", Burning Glass Technologies, 2015
Autism Screening vs. Diagnosis

**MCHAT-2 R/f - Modified Checklist for Autism in Toddlers with follow-up questions**

- Screens ASD 16 to 48 months
- Caregiver completes in 5 to 10 mins
- Simple, free downloadable scoring
- Frp call for questionable items

**ADOS-2 - Autism Diagnostic Observation Schedule**

- Psychologist trained in autism, IDD
- 60 mins to administer
- “Gold Standard” for accuracy
- Caregiver input
- Confirm ASD diagnosis

**Guidelines courtesy of American Academy of Pediatrics**
BCBA Access - Trajectory of ABA Supply and Demand

Diagnosed Children

ABA Providers

|-------------------| 24 to 30 months+ |
Beacon’s Approach to ABA Supply

Encourage providers to “gear up” to scale for new entrants
- Variable success
- Takes time
- Not all providers are interested

Encourage multi-state providers to open operations
- Trusted provider
- Knows requirements for medical necessity
- Can scale more easily

Administer training for screening and diagnosis
- Train PCP practices in administering the M-CHAT-2-R/f
- Train psychologists to perform the ADOS-2
Case Management

Addressing co-morbidities (holistic approach)

- 95% of children with ASD have at least one common co-occurring condition: ADHD, epilepsy, anxiety, depression, cognitive disabilities and gastrointestinal issues (CDC)*
- Finding the right provider: A daunting challenge as comorbidities often present differently in children with ASD; the right provider must know about ASD and the condition variances.

Care coordination for ancillary services

Caregivers of children with ASD report lack of coordination in their child’s care: Medical, educational, or social services

Caregivers receiving adequate support

Challenges facing families of ASD children: Emotional, financial, marital, and sibling impact

## Autism’s Impact on Families

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
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<tr>
<td>&gt;50%</td>
<td>Report need to stop (14%) or reduce work</td>
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<tr>
<td>&gt; 25%</td>
<td>Report spending more than 10 hours weekly to provide or coordinate special care</td>
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<tr>
<td>33%</td>
<td>Report experiencing financial burdens related to ASD healthcare and costs</td>
</tr>
<tr>
<td>46%</td>
<td>Say they need more help or information managing their emotional / physical stress</td>
</tr>
<tr>
<td>40%</td>
<td>Say they need more help or information to balance work/family responsibilities</td>
</tr>
<tr>
<td>9.7%↑</td>
<td>Parents of autistic children have a higher divorce rate than their peers</td>
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Source: American Academy of Pediatrics, National Business Group on Health and Journal of Family Psychology
Autism treatment exists in a bubble

**BH factors**
- Emotional dysregulation
- Anxiety d/o
- Trauma
- OCD
- Depression
- SIB / Suicide
- Assaultive Bx
- Dual diagnosis

**Medical factors**
- Obesity
- Sleep disorders
- Neurological
- Gastrointestinal
- Nutrition and feeding
- Intellectual disability
- Allergies/immunological

Autism Providers / ABA
Case Management

Parent training w/ supervision

Social skills based ABA

Home based ABA

Mix of individual/social skills

Basic skills/ non-severe behaviors- may involve consultation with schools

Severe behavior

Safety is primary concern/ parents may/may not participate

Home/center-based ABA

IP Discharges

Prevent readmissions/ crisis management/ support family

Inpatient

Generally longer term for most destructive behaviors

Mild/moderate cases - motivated parents

Supplement to/ shift after ABA

Continuum of Care
Applied Behavior Analysis Studies

Ivar Lovaas, UCLA (1987)
- Compared children in study with those receiving some ABA hours
- Taught language to a group of young children with autism; every child improved, some more than others
- Most services in a clinic setting
- Start before age four if possible
- Individualized goals
- Intensive supervision of staff and parents
- Parental expertise

Sallows and Graupner (2005)
- Confirmed findings of Lovaas’ 1987 study
- 48% of 23 children receiving treatment made large gains with post treatment IQ, language, and socialization scores in the average range
- Effective participation in regular education by second grade
Locations for ABA Treatment

- Home: ABA, parent training, supervision
- School: ABA, consultation, often covered by school districts
- Center: ABA, parent training, social skills group, multi-family groups, supervision: some plans place conditions on centers
- Community: grocery, dentist, doctor, barber, employer, retail
- Mixed/Multi: two or more of the above

Beacon recommends a mix of service locations including home and center-based programming.
Key to Treatment Success

Train the parents to be “ABA experts”
- The child would be able to taper off of ABA and the parents and schools could maintain the behavior gains
- In Lovaas’ study which has been replicated, nearly half of the children were able to attend regular school and were “virtually indistinguishable from their peers” needing no additional supports when they entered first or second grade

Generalization of behavior is critical to making overall gains in ABA
- An optimal treatment plan reinforces behavior across multiple environments at the same time
- ABA for most children is state-dependent; behavior that is learned in one environment does not transfer automatically to another
- Even if children are seen 40 hours a week, they are with their caregivers 80 waking hours per week and need to be involved in constant learning and reinforcement
Emerging Treatment Models

Monoculture
*df.* - the practice of producing or growing a single crop, plant, or livestock species, variety, or breed in a system at a time

How does this apply to Applied Behavior Analysis?
Emerging Models of Treatment

• Center-based treatment
  o Most focus on 2 to 6 year olds
  o Amount of parent training highly variable
  o Majority of treatment plans request 35 to 40 hours per week (regardless of severity)
  o Programmatically based- less individualized
  o Few offer home-based services
Moving Away From Monoculture

• Children over six years
• Teens and young adults—especially social skills
• Adults
• Children with severe behavior

• Parent ABA training—family and group
• Permanency planning at age 14
• Children leaving the hospital
• School-based services
• Community supports
Beacon’s ABA model – “5 Pillars”

- Early screening and diagnosis
- Collaborative care w/ BCBA care managers
- Provider practice improvement strategy
- Technology/IT portal - provider clinical data entry, in/out capability
- Evidence-based practices
Pillar 1: Early screening and diagnosis

Early intervention rewires the brain to more adaptive behaviors, leading to improved functioning.

Research shows that early treatment leads to improved learning, language abilities, and adaptive behavior, and reduced maladaptive behaviors.

The Early Start Denver Model (ESDM): A behavior therapy based on ABA methods for children 12-48 months

Compared with children who received typical services in the community, children who received ESDM showed significant improvements in IQ, adaptive behavior, and autism diagnosis – 2 years after intervention ESDM children averaged 17.6 points compared to 7 points in the comparison group.

Early intervention helps to normalize patterns of brain activity, which is associated with improved social behavior.
Pillar 2: Collaborative care with BCBA care managers

‘Get it right the first time’

BCBA care managers provide clinical direction, supervision, and case management to ensure that the care a child receives is appropriate and effective. This is made possible as all behavior is measurable data and can be compared against baseline and successive time periods.

100% of services receive prior authorization

- Providers are taught the importance of documenting medical necessity
- BCBAs validate treatment plan/progress with clinical/claims data
Pillar 3: Provider practice improvement strategy

Beacon’s ASD solution works with providers to improve the quality of the care they provide and access to it.

• Provider recruitment
  o Identify areas of need and target recruitment efforts
  o Target providers to fulfill niche needs based on severity
  o Expedite credentialing of BCBA providers

• Development and augmentation of a specialty network
  o Network screening, recruitment and onboarding
  o Peers staff provide family support

• Network training
  o Field-based Provider Quality Managers evaluate sites, programs, documentation and best practices
  o Peer-to-peer Behavior Analyst reviewers

What is a peer?

Peers work with specialty network providers to provide family support, connecting families to education, transition, housing and other services, helping with scheduling appointments, providing parental support and more.

They are either adults who themselves are on the ASD spectrum or have children with ASD.
Pillar 4: Technology solutions – treatment, measurement

Technology-enabled solutions offer multiple treatment options as well as the promotion to access and measurement of treatment efficacy

Beacon’s IT portal is the hub of clinical data
- Analytics support provider scorecards, operations, and customer reporting
- Promote treatment efficacy
  - Self-service data pull enables clinical analysis
  - Track ongoing weekly progress

Telehealth improves access, quality
- ABA remote supervision, parent training
  - May be one-to-one or one-to-many (parent training group)
- Increases access to BCBAs by > 50%
- Applicable to both urban and rural settings
  - Addresses transportation challenges
  - Solves provider shortage in rural areas
Pillar 5: Evidence-based ABA drives quality care

Following the evidence base leads to the highest quality care and best member outcomes

Evidence-based ABA practices

- Established clinical interventions: modeling, social-skills training, reinforcement, reduction in stigmatize and maladaptive behaviors
- Development of individualized treatment plans
- Measurement of the child’s progress to ensure treatment plan efficacy

Adherence to evidence-based practices

- BCBAs drive care management
- BCBAs provide provider oversight
  - Educate providers re: EB practices
  - Ensure adherence to medical necessity criteria

References for evidence-based practices

- National Standards Project, phase 2- National Autism Center
- Evidence-based Practices for Children, Youth and Young Adults with Autism Spectrum Disorder- UNC National Professional Development Center
Beacon’s current Autism services fall into four categories

- Care Coordination
- Parent Training
- Group Therapy
- Educational Resources
- W/L Support
- ABA Therapy
- Ancillary Services
- Telehealth
- Intake and Assessment
- ABA Therapy
- Group Therapy
- Family Training and Support
ABA Delivery Structure

**Beacon BCBA/Autism Care Manager**
Conducts clinical oversight, reviews treatment plans for medical necessity.

**Board Certified Assistant Behavior Analyst (BCaBA)**
Provides parent training and ABA

**Board Certified Behavior Analyst (BCBA)**
Provides clinical direction, caregiver training and case management

**Registered Behavior Technician (RBT)**
Delivers treatment protocol in person

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## Technological solutions to address challenges

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Care Coordination</th>
<th>Diagnosis</th>
<th>Tools for Caretakers</th>
</tr>
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</table>
| 1) Nationwide shortage of BCBAs  
2) Rural communities diagnostic, treatment, and support services | 1) Poor care coordination between PH and BH clinicians resulting in fragmented care  
2) ABA providers have difficulty tracking compliance of treatment | 1) Shortage of clinicians to diagnose  
2) Parents can’t capture abnormal behaviors to show pediatrician – results in delayed diagnosis | 1) Outside of the ABA therapy session, parents still need ways to work on their child’s behavior at home |
| BCBAs conduct supervision sessions via videoconferencing  
Link developmental specialists with non-specialists to educate, train, and share knowledge in diagnosis/treatment | Aggregation of data based on obtaining medical records from other providers, thus facilitating care coordination  
Software and video platforms that give clinicians ability to easily keep track of patient progress, reporting, and loop in caregivers | Conduct developmental assessment and determine using predictive analytics if child is at risk of ASD  
Use EEGs or blood test to accurately diagnose autism; technologies are still in research phase | Gaming apps help develop math, vocabulary, reading, writing, and daily living skills  
Wearables that provide feedback to enhance functioning  
Robotic aids- a non-threatening way to practice communication and social skills  
Virtual reality and augmented reality has shown benefits to increase social skills |

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**Potential Solution**
Opportunities for technology enhancement

1. Mobile apps
2. Data analytics
3. Telehealth
4. Special education apps
5. EEGs and blood tests for autism diagnosis
6. Wearable technology
7. Facilitate assessment and treatment in rural areas
8. Robotic aids for autism
9. Virtual reality solutions for autism
10. Platforms for family engagement
11. Fecal transplant
12. Medication frontiers
1. Mobile app uses predictive analytics to screen & assess

**Problems to Solve:**
1) Parents notice abnormal behavior but can’t capture/track child’s behaviors to show pediatrician – results in delayed diagnosis
2) Outside of the ABA therapy session, parents still need ways to work on their child’s behavior at home
3) There is a shortage of clinicians to diagnose ASD

**Elements**
- Developmental assessment to determine risk
- Help finding a nearby developmental specialist
- Parents can record behavior and submit data for review
- On an ongoing basis, parents can track concerning behavior
- The data is organized and easy to share
- Some apps also have a library of simple activities parents can do at home with their child
- In some cases parents have access to a clinical advisory team that can answer questions

**Solutions Offered:**
1) Assesses child and determine if he/she is at risk for ASD and help find nearby specialists if necessary
2) Application allows parents to track behaviors by taking notes, recording videos, obtain reports
3) Parents have access to simple activities they can do with their child at home that works on skills/behaviors
4) Upon FDA approval, an app could be used by clinicians to diagnose ASD

**Goal:** Give parents access to a tool that would help increase early diagnosis and be a reliable resource

**Examples**
- “EarlySee” app developed by U. of Buffalo, free download
- “Autism and Beyond” app used videos and child’s facial expressions (Apple dc’ed app after study)
- “AS Detect” from Olga Tennison Autism Research Centre is a self assessment app to determine probability for autism
- COGNOA applied to FDA as a class II diagnostic medical device for use as a diagnostic assessment tool
2. Data analytics

Problems to Solve:
1) Poor care coordination resulting in fragmented care
2) ABA providers have difficulty tracking compliance of treatment
3) No visibility to ancillary services being used
4) ABA therapy is approved without receiving proper documentation of ASD diagnosis

Elements
- Retrieve, digitize, index, code, and securely deliver thousands of medical records from millions of facilities and provider locations
- Get a complete picture of the patient

Solutions Offered:
1) Tool allows providers to obtain medical records from other providers, thus facilitating care coordination
2) Data exchange among payers, providers, hospitals, labs, pharmacies, caregivers, government agencies gives a holistic patient view
3) Would allow ABA providers to check for treatment compliance and documentation of ASD diagnosis

Examples
- Verscend/ Cotiviti
- Inovalon®

Opportunity
- Improve care coordination
- Track patient’s Medical, OT, PT, ST, Rx use of benefits
- Better outcomes
- Reduce cost of care
3. Telehealth capability to increase ABA capacity

Problems to Solve:
1) Nationwide shortage of BCBA's
2) Rural communities and hard to access areas particularly face challenges due to a lack of availability of diagnostic, treatment, and support services for ASD patients

• For autism all ABA services are delivered in-person
• Supervision and caregiver training have been shown to be as effective delivered in a telehealth format as in-person
• Telehealth can boost scarce BCBA resources by 50%
• National telehealth vendors could partner with on-the-ground providers to extend reach

Solutions Offered:
1) Telehealth capability would allow BCBA's to hold more appointment in a given day (travel time is cut out)
2) BCBA's can conduct supervision sessions as well as caregiver training via videoconferencing
3) Providers can access rural communities

Major Obstacle: Need to identify which states allow telehealth and if there are any restrictions (ex: credentialing, reimbursement); also must be approved by the customer
4. Special Education Apps for Parents and Kids

Problems to Solve:
1) Outside of the ABA therapy session, parents still need ways to work on their child’s behavior at home
2) Goal for ASD child is to complete ABA therapy and transition back into school. Kids need support to reach level of education of equivalent school-age

- There are 100s of mobile apps designed to be an educational platform for kids with ASD
- Games are considered Augmentative and Alternative Communication (AAC) which are communication methods used to help people who have speech and communication difficulties

Example: Otsimo - free download, premium with additional parental controls

Solutions Offered:
1) Applications are designed specifically for ASD kids that helps to reinforce ABA education at home
2) Contains targeted games to help children develop skills such as math, vocabulary, reading, writing, daily living
3) Provides resources to help children get to the level of public school education

Key Features
- ABA education at home – gives an opportunity for kids to work on the same types of skills that are emphasized in ABA therapy
- Targeted skills games to help develop skills such as math, vocabulary, reading, writing, daily living
- Helps to reach a level of public school education that would allow them to transition back into the system
- Ability to track child’s development and see progress reports
5. Electroencephalograms (EEGs) and Blood Tests

Electroencephalograms

- A paper submitted in May, 2018 showed EEG can accurately predict ASD in babies as **early as three months of age**
- Predictive accuracy by 9 months of age was nearly 100%
- Severity of ASD symptoms can also be predicted through projected Autism Diagnostic Observation Scale (ADOS) measurements based on the EEG readings
- Low cost, easy to use, non-invasive EEG devices are becoming available, making **routine brain activity measurements possible in a primary care setting**

Blood Tests

- Rensselaer Polytechnic Institute looked for **patterns in metabolites** in the blood relevant to two connected cellular pathways (methionine cycle and the transsulfuration pathway) suspected to be linked to ASD
- Able to predict with **88% accuracy** if children have autism
- Next Step: Replicate experiment in larger cohort recruited at multiple sites - there is promise of having a commercially available test

Problems to Solve:

1) Shortage of clinicians that have the proper training to administer the M-CHAT-R diagnostic test for ASD
2) Misdiagnosis, delayed diagnosis, and missed diagnosis
3) Doctors incorrectly give ASD diagnosis due to pressure from parents and ABA therapy is an easy, structured program to put a child in

Opportunity

While the diagnostic tool is still in the research phase, it is worth tracking these technologies

Solutions Offered:

1) EEG research shows predictive accuracy by 9 months is close to 100%
2) Research in using blood tests shows ability to predict ASD
6. Wearable technology

**Problems to Solve:**
Outside of the ABA therapy sessions, parents still need ways to manage their child’s behavior

**Solutions Offered:**
Easy-to-use, effective neurofeedback systems for safe home use by children with Autism Spectrum Disorder

**Examples**

- **Headband:** Autism Mente™ consists of a headband, an app, and cloud component. Its technology creates “tailor-made” sound neurofeedback for the child in form of auditory stimulation that stimulates brain waves that are lacking.

- **Google Glass™:** Superpower Glass encourages facial engagement and provides feedback to social interactions in the home. Sets up faces in a green box with a robotic voice cue from home-based computer.

- **Wristband:** Tracks child and can react to sensors around the home to track movement, leaving safe zones. Also can measure time in bed and sleep. Theoracare™

- **Amazon code-name “Dylan” in testing-** discern wearer’s emotional state from sound of his or her voice in concert with smartphone app based on Amazon Echo/Alexa data

- **Weighted blankets:** Vest worn under clothes with pressure controlled by an app.
7. Supporting high-risk cases in rural/underserved areas

**Problems to Solve:**
1) Shortage of clinicians with the proper training to administer the diagnostic test for ASD
2) Rural communities and hard to access areas face lack of availability of diagnostic, treatment, and support services for ASD patients

**Project ECHO®**
- Videoconferencing Technology leverages scarce resources
- Share “best practices” to reduce disparities in treating complex conditions
- Case-based learning paired with didactic lectures
- Web-based database to monitor outcomes

**Solutions Offered:**
1) Autism ECHO clinic would link developmental specialists with non-specialists to educate, train, and share knowledge in ASD treatment
2) Would increase the capacity of clinicians to diagnose ASD and BCBAs to administer ABA therapy
3) Training PCPs in screening and psychologists in performing ADOS-2

**Provider Benefits**
- Professional interaction with colleagues who share similar interests
- Access to specialty consultation and mentorship
- Establishes a good mix of work and learning
- Improves professional satisfaction/retention
- Reduces variations in care across settings
- Cost-effective care prevents excessive testing and travel
- Improves quality and safety
8. Humanoid robots that deliver developmental instruction

Problems to Solve:
Outside of the ABA therapy sessions, parents still need ways to manage their child’s behavior

Elements
- Many autistic kids have difficulty interacting with humans but are often less anxious and frequently enthusiastic about engaging with robots
- Robots are designed to be approachable for autistic children
- A non-threatening way for kids to practice their communication and social skills
- Therapists, educators, and para-professionals would use robots together with traditional intervention methods to help the child reach their developmental goals

Solutions Offered:
1) Users of robots curriculum have shown observable increases in engagement skills such as eye contact, body language, emotional understanding, friendliness
2) Can be used by parents/caretakers and professionals as supplemental tool

Objectives of robot interventions:
- Learning to pick up on emotions
- Express empathy
- Act more appropriately in social situations
- Self-motivate
- Generalize in the population

Examples:
- “Robots4Autism”- Meet Milo
- “QTrobot”
- Vanderbilt University study robot
9. Using VR and Augmented Reality Technology

Problems to Solve:
Outside of the ABA therapy sessions, parents still need ways to manage their child’s behavior

Research on Virtual/Augmented Reality & ASD
• In one study, 30 autistic children completed 10, one-hour sessions across five weeks and improved measures of emotion recognition, social attribution, and executive function of analogical reasoning.

Benefits
• VR gaming and augmented reality offer kids the opportunity to exert influence on their environment
• Kids can increase their physical exercise helping decrease repetitive behavior
• Hand-eye coordination development

Solutions Offered:
1) Research shows that virtual reality and augmented reality has benefits for autistic children to increase their social skills
2) One application projects games on the floor for kids that creates a social atmosphere and encourages physical activity

Example
• A projection screen with motion sensors that displays virtual games on the floor
• Implementing technologies in day cares and health clinics
• Anderson Center for Autism implemented the VR technology into their activities – a way for kids who have sensory challenges to get physical activity (ex: they feel pain by touching leaves on the ground

Example Image of children playing a game on the floor.
10. Programs for families

Problems to Solve:
Parents need tools understand ABA and autism, coordinate care, visualize progress

- Comprehensive understanding of child and family’s needs
- Referrals to BH providers as needed for child with autism, sibs and parents and medical providers
- Sharing data collection with caregivers
- Coaching
- Phone/video chat

Solutions Offered:
1) Caregivers can obtain video and written resources to assist in parenting
2) Parents have the ability to see the child’s progress
3) Parents can receive coaching and support

Autism Specialists search for a variety of special needs resources including respite care, in-home caregivers, financial guidance, testing and assessment resources, educational programs, schools for exceptional children, and residential programs

- Therapeutic programs and interventions
- Testing and assessment
- Educational programs
- Summer camps
- Experienced child care providers
- Aid organizations
- Adult day care and social groups
- Respite care
- Vocational training
- Care facilities and in-home care
11. Fecal transplant—Rebooting the gut

Problems to Solve:
1) Children with severe autism may have a lack of microbial gut biota
2) Children with ASD have a high incidence of GI disorders

Solutions Offered:
Fecal transplant can provide a normalized gut biome with reduction in GI symptoms and improvement in core ASD symptoms

12. Medication frontiers

Problems to Solve:
Those with autism need relief from core symptoms

- Zygel
  - Trial of cannabinoid based transdermal gel being developed for use by children ages 3 to 17 for Fragile X Syndrome to reduce core symptoms of ASD

- Balovaptan – Roche
  - Stanford study
  - Modifies the body’s response to vasopressin
  - 30 children ages 6-12
  - Initial results show improvement in “core social interaction and communication”

- Romidepsin
  - Trail of injectable cancer drug (@ 5% of administration) inhibits effect of Shank-3 mutations affecting gene expression and producing enzyme associated with decreased social interactions

Solutions Offered:
Novel medication treatments and novel use of existing medications show promise reducing core symptoms of autism

- Psychotropics
  - Aripiprazole and risperidone are only approved meds for ASD
  - Aggression, self-injury, tantrums
  - “Homeopathic doses” of psychotropics be effective in some cases
  - Critical that autism treatment providers and prescribers are in communication
Resources – Slide 1 of 2

Penn State interview with Temple Grandin
• https://www.youtube.com/watch?v=zt_G7Zw5I8c-

Examples of Autism symptoms
• https://www.youtube.com/watch?v=lbXjW-cX9kQ

PBS News Hour Autism Now Series:
• https://www.youtube.com/watch?v=Daldg7wciB0 - faces of autism
• https://www.youtube.com/watch?v=S8w50WzZnZQ - causes of autism
• https://www.youtube.com/watch?v=u02KZWMYxGY - example of child w/ severe medical issues
• https://www.youtube.com/watch?v=oh4NWmqat3I - example of public autism school
• https://www.youtube.com/watch?v=UwnaypIzUoo - autism after age 21
• https://www.youtube.com/watch?v=6XCU1-mOzGI - public health response

Dateline NBC- “On the Brink” 7 Part Series
• https://www.nbcnews.com/dateline/video/full-episode--on-the-brink-430803523969
Resources – Slide 2 of 2

Autism Speaks

• Autism Speaks toolkits- 8 languages
• [https://www.autismspeaks.org/autism-speaks-tool-kits](https://www.autismspeaks.org/autism-speaks-tool-kits) Feeding, sleep, safety, puberty, constipation, transition, behavior, employment, 100 day kit for newly-diagnosed children, financial planning, toilet training, etc.
• Autism Speaks YouTube channel- [https://www.youtube.com/channel/UC3FPy4hb6A_oIkToWVfxeQA](https://www.youtube.com/channel/UC3FPy4hb6A_oIkToWVfxeQA)

Books

• “The Curious Incident of the Dog in the Nighttime” by Mark Haddon
• “A Parent’s Guide to High-Functioning Autism Spectrum Disorder” by Geraldine Dawson, James McPartland and Sally Ozonoff
• “Look Me in the Eye- My Life with Asperger’s” by John Elder Robison
• “Life, Animated: a Story of Sidekick, Heroes and Autism” by Ron Suskind
• “Aspergirls: Empowering Females with Asperger Syndrome” by Rudy Simone
• “The Official Autism 101 eBook” by Karen Simmons

IACC- Interagency Autism Coordinating Committee

• Coordinates activities related to autism for Department of Health and Human Services- [https://iacc.hhs.gov/](https://iacc.hhs.gov/)
Questions?