Meeting the Needs of Adults with ASD: Issues and Considerations

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The Eden II/Genesis Programs
The Issues

- The incidence of autism has risen dramatically in the past 20 years
- Individuals with autism require highly specialized treatment
- Many individuals with autism require high intensity programs
- Services and funding are not guaranteed after 21 years of age.
- Adults with autism are not children with autism
Adolescents and Adults with ASD

- We are children for approx. 18 years

- We are adults typically for well over 50 years.

- Despite the fact that there are significantly more adults with autism than children, there is very little research or outcome literature on this population.
Developmental Course

• Improvement
  – Some evidence that a group of individuals with ASD demonstrate improvement in behavior, language and social skills in adolescence.
  – Most, however, will continue to need some type of support across the lifespan
Developmental Course

• Deterioration

– Some evidence of regression or development of new behaviors in adolescence in 20-30 % of individuals with ASD
Developmental Course

- Behavioral Difficulties
  - Many parents report significant behavior problems
    - Resistance to change
    - Unacceptable sexual behavior
    - Compulsive behaviors
    - Aggression and self injury (that is more difficult to manage to increase in size and strength)
Developmental Course

• **Intelligence**
  
  – Two types of changes

  • Improved IQ scores in children after intensive programming (specifically ABA)

  • Degree of MR increases so that more adolescents and adults would be considered moderate to severe MR compared to mild to moderate in early childhood

  • Prevalence of MR and autism ranges from 20% to 80%
Developmental Course

• Language
  – Overall improvement in most children as they get older in receptive and expressive language

  – Higher incidence of articulation and prosodic problems in adolescents and adults with ASD than cognitive matched peers

  – Speech prior to five years of age is an indicator of a better prognostic outcome. However, it doesn’t mean that children who do not have speech by five won’t develop it at all.
Developmental Course

• Adaptive Behavior
  – Adaptive behavior is typically much lower than IQ in individuals with ASD
  – Despite near normal IQ, many adults with ASD continue to demonstrate significant adaptive behavior limitations
Developmental Course

• Academic Achievement and Higher Education
  – Educational achievements have improved over the past decade
  – Typically, however, academic achievement continues to fall below IQ expectations
Psychiatric and Emotional Problems

- 40% of individuals with ASD experience some psychiatric “episode”
- Mood disorders are most common
- Depression is most common of mood disorders in adults with ASD
- Higher incidence of mood disorders in families of individuals with ASD
20-33 % of individuals with autism have a seizure disorders

Bi-model onset of epilepsy in ASD
- 25-40 %: onset prior to age 5
- 50 %: onset in adolescence or adulthood
Mortality

• Less than 50 years ago, the average age of death for an individual with ID/DD was approximately 35

• Fortunately, today, the average age of death is within 10% of the average age for non-disabled adults

• This means that many adults with ASD will outlive their parents
Specific Challenges
Adolescents and Adults

• Dr. Catherine Lord, Chairperson of a Panel of Experts convened to examine services for children with autism found that fewer than 10% are receiving appropriate services in the United States.

• Even with good services, many individuals with autism have significant unmet challenges as they become adolescents and adults.
Challenges

• Traditional adult service models do not address some of the unique and significant differences in individuals with ASD
  – Significant social deficits
  – Issues with independence
  – Travel issues
  – Communication
Challenges

• May not be able to fade supports
• Low frequency high intensity behaviors
• Staffing intensity and cost
• Lack of evidence based practice
Social Skills

- A key to getting a job is having the skills needed to perform the job
- A key to KEEPING a job is having the social skills needed to act appropriately
Social Skills and Conduct

- Issues with personal space
- Talking too much on the job
- Inappropriate statements
- Defiance, rudeness or hostility
- Non-compliance
- Issues with hygiene
- Lack of leisure skills
Independence

• Prompt dependency, self-stimulatory behavior and issues with motivation all contribute to issues with independence in adults on the autism spectrum.
Independence

- Independence -
  - Freedom from the support, influence, support, and aid of others

  - A competency
ASD and Independence

• Many individuals with ASD are capable of acquiring a broad range of skills.

• The problem is that learners with ASD are often unable to continue to demonstrate these skills once professional support is faded.

• They may depend on adult presence to remain engaged to complete an activity.
What are the Challenges to Independence for Learners with ASD

• Distractibility caused by internal or external factors
  – Internal distractors: self stimulatory behaviors
  – External distractors: could be anything that interferes with attention
What are the Challenges to Independence for Learners with ASD

• Independent initiation

  – Research indicates individuals with ASD may lack ability to “get started”

  – Tend not to be self directed
What are the Challenges to Independence for Learners with ASD

- Failure to attend to relevant stimuli - in turn resulting in prompt dependency
  
  - Children may overselect on the prompt (often inadvertently provided by adult) and therefore not complete an activity or task in the absence of the prompt
  
  - Children with ASD are “taught” to be prompt dependent

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What are the Challenges to Independence for Learners with ASD

• Lack of motivation
  – May be dependent upon artificial motivation systems
  – May be unable to see the “big picture” which affects motivation to complete a task or activity
What are the Challenges to Independence for Learners with ASD

• Issues with executive functioning
  • Planning
  • Sequencing
  • Perseveration
  • Processing speed

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Outcome Studies

• Studies indicate that outcomes for adults with ASD are quite poor

• In a survey of over 700 school personnel, respondents indicated that the students with disabilities (including ASD), spend over 86% of their day within 3 feet of an adult
Several years ago, we began to evaluate the levels of independence of our teens. We objectively defined “independence” and measured the students’ performance under different conditions.
Results

Independent Performance of Preferred Activities

- less than 10 minutes
- less than 20 minutes
- 30-60 minutes
- more than 60 minutes
Results

Independent Performance of Neutral or Non Preferred Activities

- less than 10 minutes
- less than 20 minutes
- 30-60 minutes
- more than 60 minutes
Results of Assessment

• Less than 20% of our participants could stay on task for more than 20 minutes with a neutral or non-preferred task.

• In fact, the majority could not stay on task for more than 10 minutes.

• This means that most can **not:**
  - Shower or bath without support
  - Prepare a sandwich without support
  - Get a job
Transportation Issues

- Difficulty with transportation has been cited as one of the major obstacles to employment for people with ID/DD

- Research has shown that adults with autism have significantly more challenges with accessing transportation than people with ID/DD without a diagnosis of ASD
Why the Increased Challenges

- Resistance to change
- Poor judgement
- Challenging behaviors
- Challenges with social skills
Communication

- May rely on AAC
- Challenges in language comprehension
- Gap between comprehension and production can lead to confusion
- Deficits in social language
Low Frequency-High Intensity Problem Behavior

• It only takes one tantrum in the workplace to result in termination

• Sometimes staffing needs continue to be high due to the “possibility” of the problem behavior
  – Funds for this staffing, however, are often not available due to the high level of functioning all the rest of the time

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Staffing Issues

• Turnover rates in adult services for individuals with ASD has been cited as high as 50 %

• Vacancy rates can be as high as 20 %
Staffing Issues

- Challenges include:
  - High need for male staff
  - Lack of training
  - Limited supervision and support
  - Poor rates of pay
  - High rates of challenging behaviors in many adults with ASD

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Evidence Based Practice

- There is an abundance of evidence to document that teaching children with autism using the principles of ABA results in best outcomes.

- There is also an abundance of literature in reduction of challenging behavior and increasing or decreasing specific target behaviors.

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Evidence Based Practice

There is very little literature, however, providing adult services practitioners with evidence based strategies to achieve best outcomes in employment, friendship and other areas related to adulthood.
Review of the Literature

• In 2009, Gerhardt, in collaboration with a Think Tank of experts in the field published a paper on the State of Services for Adults with ASD.

• The found that outcome studies of adults with ASD revealed that the last majority of adults were unemployed or underemployed.
Gerhardt (2009)

• The majority of adults with ASD were living with parents, siblings or other relatives

• Transition requirements as required by IDEA were poorly implemented

• Access to appropriate residential and employment models were greatly restricted due to inadequate funding

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Shattuck et al., 2013

- Reviewed the literature from 2000-2010
- Searched over 11,000 studies and found only 23 met criteria for inclusion in their review
- Most studies addressed employment as well as specific behavior interventions
Shattuck et al., 2013

• Reviewed report on state of services for adults with autism in US. This report revealed:
  – High unemployment
  – Families were primary caretakers
  – High staff turnover
  – Inadequate transition planning
  – Pervasive gaps in the need for services and service availability

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Green et al. (2000)

- In a group of 20 adolescents with Asperger syndrome, Green, et al (2000) found that despite a mean IQ of 92
  - Only half were independent in most basic self care skills including brushing teeth, showering, etc.
  - None were considered by their parents as capable of engaging in leisure activities outside of the home, traveling independently, or making competent decisions about self care.
• Howlin, et al (2004) surveyed 68 adults with autism with an IQ of above 50 and found a majority (58%) were rated as having poor or very poor outcomes. With regards to employment status they found
  – 8 were competitively employed
  – 1 was self employed earning less than a living wage
  – 14 worked in supported, sheltered or volunteer employment
  – 42 had “programs” or chores through their residential provider.
Summary

• There are a number of additional studies on adults with ASD with similar outcomes already described.

• For an excellent review of the literature and the historical perspective, see Shattuck et al. (2013) and Gerhard (2009).
Summary

• Most have concluded that the primary reasons for the poor outcomes include:
  – Poorly implement transitions from schools to adulthood
  – Lack of knowledge or understanding of effective models to achieve employment or community integration
  – Lack of integration of services
  – Lack of qualified staff

Eden II Programs
Day Programs and Employment
Day Programs

- There are two primary funding streams for adult day services

  - Vocational Rehabilitation
    - Provision of time limited services needed to achieve independent employment
    - Include services such as counseling, job training, employment support etc.

Eden II Programs
Day Programs

• There are two primary funding streams for adult day services

  – HCBS Waiver
    • Traditional Medicaid (and state funded) model to fund program and services
    • Today, some states are moving away from funding programs and funding individuals instead. Through self determination, individuals purchase the services needed to work and live in the community
Self Determination

- https://www.youtube.com/watch?feature=player_detailpage&v=EwAr0axog6c
Day Program Models

• **Sheltered Workshops**
  - Old model of adult day programs
  - Many states are fading out sheltered workshops
  - Primary purpose was to provide large enclave-like employment experiences
  - Original intent for sheltered workshops was as a transition placement to employment
    - History showed that for most adults in sheltered workshops, this was the final placement
Day Program Models

- Day Habilitation
  - Tends to be congregate, facilities based program designed to address all areas of daily living, employment, recreation, etc.

  - Funded through HCBS Waiver

  - Quality of program varies widely from program to program and state to state

Eden II Programs
Day Program Models

• Day Habilitation
  – New York State recently implemented a variation of the Day Hab program

• Day Hab Without Walls

• Designed to insure high rates of community access and integration
Employment Models

• Supported Employment
  – Provision of sufficient supports to achieve independent employment
  – Employment specialists attempt to match an adult with a job, provides needed support to facilitation transition to natural supports
Models of Supported Employment

• Individual Placement Model

• Clustered Placement (Enclave)

• Mobile Work Crew

• Entrepreneurial Models
Entrepreneurial Models

• First Business Summit on Employing Adults with Autism was convened in 2014 North Carolina with Focus on Unique Role for Small Business

Eden II Programs
First Business Summit Conference

- The goal of the conference was to spark a national movement where an increasing number of small businesses and entrepreneurs create self-sustaining businesses to meet the needs of their local residents while providing a range of jobs that match the skills of people with autism and developmental disabilities.

Eden II Programs
Model Programs

• Arthur & Friends, based in Newton, NJ, which operates greenhouses that employ disabled adults who grow and market hydroponic produce

• Aspiritech, headquartered in Chicago, which employs high-functioning adults with autism as part of a workforce that conducts domestic software testing and provides other quality assurance (QA) services
Model Programs

• Autistic Global Initiative in San Diego, whose members on the autism spectrum provide professional and consulting services to a range of industries.

• AutonomyWorks, in Chicago, which leverages the unique talents and abilities of people with autism to deliver technology services, such as website maintenance, reporting and quality assurance, to companies of all...
Model Programs

• **Beneficial Beans**, a Phoenix-based café that trains adults with autism spectrum disorders and provides employment opportunities

• **Inclusion Films Workshop** in Burbank, CA, which provides vocational training and an entry-level knowledge of film and TV production to adults with developmental disabilities
Summary

• A number of viable models for promoting community integration and employment for adults with ASD are available on a State by State basis.

• Despite this, the unemployment rate and community access for many adults with ASD remains a problem.
Summary

• **Ongoing Challenges:**
  – The most significantly behaviorally challenged adults
  – The lack of independence
  – The poor transition planning and lack of coordination between schools and adult services
Recommendations

• Transition planning should occur as early as possible—most particularly for those individuals with significant challenges.

• Employment, independence, recreation and leisure along with community integration should be the focus as early as possible.
Recommendations

• Staffing and funding is far better in the education programs than post graduation.

• Job sampling needs to occur as young as 14-15

• Job placement should follow as young as 16-17
Recommendations

• Challenges that need to be addressed:
  – Education policy
  – Transportation
  – Curriculum focus
  – Parental views
  – Student views

Eden II Programs
Residential Opportunities

- The question of “where will I live?” or “where will my son or daughter live?” is inevitable in the lives of adults on the spectrum.
- While there are adults on the spectrum who can live independently, many more require supports across their lifespan.
- In some cases, these supports may be minimal or temporary while in other cases they may be permanent and around the clock.
Residential Opportunities

• The National Association of Residential Providers of Adults with Autism (NARPPA) reports a national crisis in services for adults with DD
  – The crisis is most notably in residential opportunities and most significantly for adults on the autism spectrum
Olmstead Decision (1999)

• Deemed unnecessary institutionalization of people with disabilities constitutes discrimination under ADA

• In 2009, President Obama issues a proclamation launching the “Year of Community Living”
• **Defining “institutional living”**
  – Self advocates defined institutions as:
    • 3 or more people who have NOT chosen to live together
    • Residents are not permitted to lock bedroom or bathroom doors
    • Regimented mealtime, etc.
Issues Today

• As of 2008, 85% of all institutionalized populations lived in 18 states.

• Texas was listed as the #1 State with 14% of the population living in institutions.
Residential Models

- Transition models
- Supported living
- Supervised living
- Accommodated living
- Group home living
- Farmstead programs
- ICF
Transitional Models

• Offer relatively short term residential experience (1 month-2 years) with goal of transition individual back to the original environment

• 3 types:
  – Intensive in-patient behavioral evaluation
  – Intensive lifeskills training to promote independent living
  – College support programs

See Gerhardt (2009) for examples of these programs

Eden II Programs
Residential Opportunities

• Supported Living Models

• Provides supports to individuals who live in self owned or leased homes or apartments
• Effective when community of supports are build around the individual
• Supports can range from assistance in managing finances, cooking, transportation

Eden II Programs
Residential Opportunities

- **Supervised Living**
  - More support and services than supported living but less than a group home
  - Often have 1-2 individuals living in house or apartment
  - May have several in close proximity
Residential Opportunities

- **ICF-MR**
  - Larger congregate care residential program
  - Seen today as institutional living
  - Highly regulated by the state
Residential Opportunities

• Group Homes
  – Houses located in the community
  – Typically fewer than 8 individuals residing together
  – 24 hour staffing provided by a provider agency
  – Generally, home is owned by the provider agency
Issues Today

• Traditional 24 hour supervised group homes are now being criticized as being institutional.
• Efforts are being made to move to small residences with 2-3 individuals living there
New York State Example

- NYS has issued their new initiative called the Transformational Agenda
- Transformation Agenda Goals
  - Creative independent living with 1-2 individuals residing
  - Employment for all
  - Natural circle of supports
The Future Crisis

• Individuals with significant autism are generally the most complex and expensive to support (along with medically fragile)

• Appropriate and safe models of living will become less and less
Other Models

- Farmstead Programs
- Teaching Family Models
- Neighboring Networks

Eden II Programs
Farmstead

- Residential model within the concept of a working farm
- Isolated by nature of the location
- Community integration is generally provided within life on the farm and its workers
Teaching Family Model

- Teaching-Parents live in the home (often in a separate part of the home) and provide a set number of hours per week of supervision and direct support (40-60 hours per week)

- The turnover may be less due to the fact that the Teaching Parents are given free living quarters for the time of their employment
Neighboring Networks

- Currently being explored in NY
- Concept is a group of families (with our without a provider) collaborate with a real estate developer.
- The developer relies on state initiatives such as 80-20 programs to secure a set number of apartments be set aside for people with ASD
Neighboring Networks

- Proposal is for themed environments
  - Artist community
  - Horticultural-farming
  - Retail (on first floor)
- Day programs take place within the community
- Natural supports are a key focus

Eden II Programs
Summary

• There is a residential crisis in our country now for people with ASD that is only going to get worse with the numbers entering adulthood

• We must be careful not to throw the baby out with the bathwater with regard to models of residential development
The Problem...

- How to define good outcomes
- Consider this:
  - Using today's "measures of good outcome" and an individual who enjoys his house, goes shopping for groceries with his friends, attends Friday night dances with his housemates and volunteers 3 days a week at a nursing home would be considered in the Poor Outcomes Group
  - His house has 8 residents and he is not gainfully employed
A Different Way..

- Ruble & Dalrymple describe a different way of measuring outcomes
- They discuss a model called:  
  – Personal Environment Fit Perspective
- This model allows each individual’s outcomes to be counted based on them as opposed to a standard set arbitrarily
Summary and Conclusions

• Despite advances in the education and treatment of children with ASD, little gains have been made in outcomes for adults with ASD.

• The number of adults with ASD entering our system in the next few years is staggering and we must develop more effective strategies to meet this challenge.
Recommendations

• Transition planning must improve

• Funding is best prior to 21

• For all levels of ASD, things must change in order to improve our outcomes
Level 1: HFA and AS

• Most individuals are in general education

• Many spend all of their time in academic programs with the goal of attending college

• There is little to no focus on providing them with the social skills, job skills and leisure skills needed to succeed as an adult

Eden II Programs
Level 2

• These are individuals with access to both general education and support in autism specialty programs

• There is often unclear goals as to where these individuals will go when they age out of the education system
Level 3

- These individuals are typically in self-contained ASD programs.

- Communication between school age providers and adult services providers is often minimal or non-existent.

- Staffing ratios are typically 50% less once you turn 21.
Priorities of Instruction in Transition Programming

• Solicit student and family input as to where they want to be in 1 year, 5 years, 10 years, etc.

• Survey current and potential future environments.

• Assess skill needs across environments in terms of work, social and navigation skills.


Eden II Programs
And ...

- Prioritize skills that occur across multiple environments
- Attend to safety skills
- Attend to skills that reduce dependence
Some Things to Think About

• What is the real objective or goal?
  – For example, going to the bathroom...

• Is this learner able to perform this task without assistance?

• Is this learner able to perform this task without someone present to keep them focused or prevent problem behavior
Setting Goals

• Must begin each year with a complete skills assessment. This must look at skills that are critical for good outcomes for teens.
  – ADL
  – Communication
  – Recreation – Leisure
  – Job skills

Independently
Think Long Term and Big Picture

• Where is this individual going to be in five years?

• What are the obstacles to independence?

• What can be taught and what can be adapted?
Other Issues to Consider

- Parents
  - The may be pushing a different agenda
  - They may be secretly wishing you would push a different agenda
  - Either way, it will take good communication
Other Issues to Consider

• Your own biases and experiences
  
  – It is much easier to teach a child to match, sort or identify something at a table than it is to teach that child to get dressed independently or take a shower without assistance
  
  – It is easier to take data and see progress in those same goals but….
Other Issues to Consider

• Are you teaching the teen with ASD to understand “employment”.

• Are you teaching the parents of the teen with ASD to understand “employment”
Conclusions

- These are the questions you should be able to answer for each program you are working on:

1. What is the purpose of this goal?
2. How long have I been working on this?
3. Is this going to impact on this teen’s life in the long run
4. If this teen does not acquire this skill, will someone have to do it for him/her later in life
Conclusions

These are the questions you should be able to answer for each program you are working on:

4. Am I teaching this skill to independence?
5. If not, what are the barriers to independence and how should I address these?
Final Considerations

• In addition to preparing the individual with ASD for employment and independent living, there are several other critical areas that must be addressed:
  – Safety skills
  – Lifelong recreation and leisure
  – Sexuality
Safety Skills

• In the past 5 years, there have been more and more cases of elopement resulting in tragic consequences.
  – As we move to more community integration and less structured environments, we must insure our participants have the skills they need to navigate the natural environment.
Life-Long Recreation and Leisure

• Most of us begin developing “hobbies” and leisure activities during adolescence.
• It is important that we address this in our participants as well, particularly those with significant challenges.
• For some, it is through recreation and leisure activities that community access is most relevant.
Examples

- Yoga and working out at local gym
- Running and joining running clubs
- Drama and joining local theatre clubs
- Fishing clubs
- Etc
Silent Running

• The story of two young men with several challenges
• Both have significant challenging behaviors, remain non-verbal and require supervision at all times....
  – Except when running
As Seen on Good Morning America and in the New York Times

Our Family’s Journey to the Finish Line with Autism

SILENT RUNNING

ROBYN K. SCHNEIDER

with KATE HOPPER

Eden II Programs
Role of BA

• Assist in the development of outcome measures that are objective and measurable for adolescents and adults with ASD

• Contribute to the evidence based literature in adult services
Role of BA

• Focus on sustainable models of behavior management

• Focus on teaching skills to true independence

• Develop training models for direct care workers
Role of BA

• Expand role of OBM within residences for individuals with ASD

• Develop evidence based programs in areas such as
  – Community safety
  – Social skills training
  – Sexuality

Eden II Programs
Eden II Model

- Begin transition planning at age 10
- Begin job sampling at age 14
- Begin supported employment at age 16-18
- Transition to natural supports - Age 18-21
Eden II Model

• Create school environment that promotes skill acquisition in areas that are critical for success in adulthood

• Move away from traditional classroom environment
Eden II Model

• Recognize the need for a continuum of services
  – Maintain tradition day hab program with focus on volunteer work, recreation and leisure and community integration
  – Maintain mobile work crew and enclave employment opportunities
Eden II Model

- Recognize the need for a continuum of services
  - Develop entrepreneurial business models
  - Supported employment models
  - Recreation and leisure opportunities
Last Thoughts

- Put your money where your mouth is..

Hire a person with ASD
Thank You

www.eden2.org