

A Person-in-Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Prepared for the Center for Healthy Families
November 9, 2011

By Jonah Green, LCSW-C
Jonah Green and Associates
3930 Knowles Avenue Suite 200
Kensington, MD 20895

www.jonahgreenandassociates.com

301-466-9526

A Person-in-Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Outline

- Introduction: A Person-in-Environment Approach to the ASDs
- Understanding the Disorders: Symptoms, Behaviors, Diagnoses
- Understanding the child: emotional and interpersonal experiences
- Understanding the family experience: Individuals and relationships through the life cycle
- The Broader Social Context
- Making the Diagnosis
- Medical, educational, and social treatments/resources
- Treatment: Engaging the Family
- Treatment: Addressing Parenting Issues
- Treatment: Working with the Individual Child
- Treatment: Strengthening the Family
- Conclusion

A Person-in-Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

What is a Person in Environment (PIE) Approach?

- The PIE approach views the autistic child as interactive with his or her multiple environments, with each part of the environment and the individual affecting each other (Hare, 2004). The therapist can intervene with the individual child, with any individual or system impacting the child (such as parents or sibs), or with a relationship between two people or systems in the child's environment (such as between a family and a school).

Why a Person in Environment approach to ASDs?

- Autism is a genetic disorder that exists independent of the social environment; interventions directed at the individual can greatly impact the individual's well-being
- People with ASDs have a profound effect on their environments, particularly the family
- The family, educational, and social, environment all have a great impact on the child with ASD.
- The **family environment in particular** is crucial to the child's success, not only because of its day to day impact, but because a well-functioning, informed family is the best advocate, support, and "treatment manager" for the child
- The child with an ASD can pose particular challenges for each family member, family relationship, and the family as a whole; addressing these challenges can positively impact the child, creating a positive reciprocal cycle.

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Part I: Understanding the Disorders: Symptoms, Behaviors, Diagnoses

- Neurological disorder which can be diagnosed in first 3 years. Consists of impaired language processing/communication, social skills deficits, difficulty modulating sensory systems. Often odd/out of place/concrete language. Behavior often repetitive, restricted. Often rigid, black and white thinking; difficulty understanding social cues, perspective-taking. Usually difficulty in fine/gross motor functioning.
- Typical behavior issues: difficulty with transitions; difficulty modulating emotions, managing frustration; impulsiveness, violence; self-injurious behaviors; meltdowns; can be reactive to/drawn to/withdraw from sensory experiences; sexual acting out; lack of attendance to ADLs; chewing, flapping, twirling, picking; running away; screen addiction.
- A “spectrum”, from those that are non-verbal with severe behavior problems to high-functioning people who are intelligent, have impaired social skills
- The 5 discrete diagnoses: Autistic D/O, Asperger’s, PDD-NOS, (Rett’s, Disintegrative D/O). Asperger’s lacks delay in verbal IQ, PDD-NOS lacks all symptoms of AS. New issues in Dx—may drop Asperger’s, add PDD categories
- Additional symptoms/challenges for people on the spectrum: sleep, allergies, GI issues, asthma
- Many theories of etiology
- Epidemiology: latest studies suggest 1 in 100 children, 1 in 70 boys. Some evidence that a portion may not have symptoms of ASD by adulthood

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Understanding the Child: Emotional Experiences

- Feeling disrespected/devalued, ignored
- Feeling rejected/unloved/lonely/misunderstood/embarrassed
- Sense of unworthiness; feeling there is something “wrong with them”
- Guilt, especially following violence
- Feeling inadequate/incompetent/confused
- Humiliation (esp. from public meltdowns)
- Feelings of power/belonging/significance may stem from negative behaviors and disabled “status”
- Feels victimized, indignant, “entitled”
- Feels discouraged, frustrated
- Pervasive anger/envy; revenge fantasies
- Boredom/lack of purpose
- Fears/anxieties/obsessive perseveration

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Understanding the Child: Interpersonal Experiences

- Difficulty making friends; connecting with others; being ignored
- Being overprotected/coddled/talked down to
- Constantly “in trouble”; punished, yelled at
- Being stigmatized and/or labeled
- Being scapegoated
- Teasing/bullying/abuse
- Failure in academics and other areas
- Gaining power/attention from disability/helplessness/behavior issues
- Difficulty matching achievement of siblings, becoming more evident as enters adolescence
- Discrimination/being talked down to, disrespected
- Difficulty impacting others/environment through positive behaviors

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Understanding the Family Experience: The Family as a Whole

- Overall Family Dynamics: time/resource demands, stigma, isolation, trauma (esp. with violent and chronic behaviors), feelings of guilt/blame, shame, parental strife, other family member's needs and relationships are not addressed due to overwhelming needs
- Grief/disappointment constant part of experience. The Stages model: shock, denial, anger, bargaining, acceptance.
- Grief is typically expressed less evenly than the Stages model. Family members can be at different stages, and often face grief at each developmental stage
- Common Ways of Coping with grief/upset: *Normalization* (addressing autism within the context of other needs), *Crusadership* (illness as an occupation), *Altruism* (can neglect own needs), *Resignation* (can lead to depression)
- Positive effects of having an autistic member of the family: increased cohesion, empathy among siblings, increased creative problem-solving, personal growth

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Challenges for Families through the Child's Development

- Infant and Toddler Stage: the stress of diagnosis, difficulty bonding, negotiating different family reactions, finding supports
- School-Age: Need for advocacy, arranging treatments/child care, managing behaviors; attending to sibs
- Adolescence: coping with chronicity, isolation/peer rejection, need to build functional living skills, facing dangerous tantrums
- The Transition to Adulthood: coordinating services, resentment/loss for parents/sometimes sibs as they have difficulty moving on in face of caregiver demands
- Early adulthood: maximizing independence and supports/ongoing demands, even as parents may become ill or less functional. Siblings and extended family may need to take on increasing role.

Grief/loss tends to re-appear at each new developmental stage

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Challenges for Particular Family Members

- Parents: may experience fright, overwhelm, guilt, shame. Self-esteem may be affected. Anxiety and depression may ensue. Often overwhelmed by time/resource demands. May react by distancing, protecting/doing for, neglecting own needs.
- Siblings: may feel neglected, deprived, angry/jealous at attention, “cheated”, embarrassed, “survivor’s guilt”. May react by acting out, protecting/doing for, act “parentified”, “hiding” sibling
- Grandparents: may feel guilty, angry, ashamed. May have difficulty understanding behaviors, and ascribe them to bad parenting. May react by over-involvement, neglect, criticism of parents, extending support and resources
- Extended family: often distant, may resist contact with child/family, especially if behaviors are problematic

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Typical Challenges for Family Relationships

- “Mother-Father”: fights over diagnosis, parenting approaches, spending of time/resources, effectiveness of particular treatments; enmeshment vs. disengagement
- “Mother” (typically)--Autistic Child: May “do for” autistic child; child may become more dependent, may act out on Mother
- “Father” (typically)--Autistic Child: May be rejecting/withdrawing, focused on discipline/behavior and achievement
- Either parent—non-autistic child: may neglect needs of child, pressure child to care for or ‘make up’ for autistic child; may favor child
- Autistic child-non-autistic child: may be distant/ often competitive, non-autistic child may take protective/parentified role
- Grandparents-parents: may be critical and intrusive, can be neglectful and non-supportive

Caveats: all families and relationships are different; the presence of the autistic child can also have positive effects (more family cohesion, more empathy, personal growth)

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

The Broader Social Context

- More affluent families often have more resources/knowledge, may experience more panic/grief (less place in culture for child) and more strained family dynamics. Less affluent families may be less likely to advocate/treat, can be more accepting.
- Certain cultural/socio-economic groups may have more supportive extended family/community networks.
- Children/families often experience rejection, especially if there are behavior problems/inappropriate placements
- Continuum of public services: programs for infants and toddlers through Developmental Disabilities Administration in early years, system of Special Education (Section 504, Individualized Education Plan) for older children
- Variety of medical/mental health treatments, paid by medical insurance, self-pay: Occupational Therapy, Speech and Language therapy, social skills groups
- Advocacy groups can offer support/guidance. Places where children get treatment are frequently where parents can find community/support. Also list serves and other online supports
- Systems/helping professionals and families are often at odds, even as many helpers have family members with ASDs; many families feel judged and used, and often have sense that professionals don't "get it"
- SSDI offers an avenue for money and public insurance; often done through lawyers who can also help with financial planning (esp. special needs trusts)

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Treatment: Making the Diagnosis

- Early warning signs: little eye contact/vocalizations at six months, impaired speech/responsiveness at 12 months, over/under-sensitivity to stimuli at 24 months: not initiating words, loss of words
- Medical Screenings: Modified Checklist for Autism prior to 24 months, Autism Treatment Evaluation D/O checklist for older children
- Full assessments: neuropsychological evaluations (including educational/intelligence testing), occupational and speech evaluations
- Diagnosticians: Psychologist, OT, SPLP, PT, developmental pediatrician, educators, social worker
- The Various Rating Scales: Gilliam, Autism Rating Scale; functional assessments
- Resources for making the Diagnosis: Hospital-based clinics/DDA/School System/Private providers
- Differential Diagnoses: OCD, ADHD, Social Anxiety, auditory/vision problems
- Co-Morbidity: OCD, ADHD, mood issues, allergies, asthma, intellectual disability

Diagnostic questions are often inconclusive and can contribute to divisions in families

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Medical, Educational, and Social Service Treatments and Resources

- Characteristics of successful approaches: begin early, intensive, involve family, structured, utilize behavioral principles, offer a balance between capitalizing on strengths/helping kids feel “normal” , and skill-building
- Applied Behavioral Analysis; intense, specific skill-building
- TEACHH: visual structure and organization
- LEAP: educational inclusion
- Picture-Exchange Communication Systems: communicating with pictures
- Greenspan/DIR Model: child-centered play to develop reciprocity/empathy/engagement
- Social Skills Groups: teaching specific skills
- Educational Supports (504s, IEPs, accommodations/special programs)
- Educational approaches: Multi-sensory instruction, “sensory breaks”, lots of structure
- Educational programs: Fast-forward, Cogmed, Kurzweil

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

More Treatments, Approaches, and Interventions

- Speech and Language Therapy: developing pragmatic communication skills; building language comprehension
- Occupational Therapy: developing practical motor skills, sensory integration therapy to modulate sensitivities
- Physical Therapy: building gross motor skills
- Medication: anti-depressants, stimulants, anti-psychotics to address mood, behavior
- Dietary Interventions: reducing gluten and casein, adding Omega-3s; GI specialists/nutritionists
- Emphasizing Strengths; memory, visual abilities, intense interests, etc.
- Individualized sports: karate, tennis, swimming, yoga
- Fitness/sensory programs which include social skills
- Neuro-feedback: increasing self awareness and self-control
- Mentor programs
- Play Dates/Controlled social events
- Managing/finding alternatives to screen time
- Social Stories: improving behavior and teaching skills

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

A PIE Approach to treating children and adolescents with ASDs: an Overview

- General Approach: To work with the child and family in an integrative way, offering support and understanding, building capacity of child and family to foster development, improve order/behavior in the home, strengthen family structure/family cohesion, improve relationships with systems and individuals outside family, advocate for child, and manage the treatment.
- Clinician must be able to “talk the talk” of symptoms, diagnoses, resources, etc.
- Realize that children and families have often felt judged and rejected by professionals; avoid pat advice
- Important for clinician to gain an understanding of the perspective of all family members and develop an understanding of family structure/roles/relationships
- Need for clinician to avoid implication that family is responsible for ASD: “Family is integral to the solution, but is not the problem”.

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Engaging the Family: Initial Sessions

- Assess knowledge of nature of child's autism and services, review diagnostic evidence/documentation
- Ask about role/perspective of all household members up front
- Inquire about the well-being of the family as a whole, each family relationship/sub-system
- Affirm the importance of family environment, and role of family as the "Treatment Manager" and advocate
- Ask about access to/relationship with medical, educational, and social service systems, supports and relationship to extended family, community, school, etc.
- Begin trouble-shooting with family about ideas for generating order, obtaining resources and supports, reducing stress
- Assist the family in planning for the future
- Consider time and resource demands in making any suggestions

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Addressing Parenting Issues

- Work with all caretakers to develop a unified approach
- Emphasize **proactive planning**. Attempt to give children a productive role/build on strengths.
- Generate an encouraging atmosphere; consider “special time”
- Emphasize routine, ritual, and structure; build time for transitions/breaks
- Identify/address problem areas and triggers/address safety concerns
- Offer hope; celebrate progress

Addressing negative behaviors:

- -Generate positively framed, clear/concise expectations
- -Consider visuals to encourage desired behavior (i.e., bedtime rituals sequences or pictures *(do this, not that)*)
- -Help parents recognize stressors/warning signs
- -Build behavior management skills: redirection, limit setting/logical consequences (behavior charts if works for family); advise of pitfalls of punishment, lectures, angry tone
- -Help parents address underlying needs (i.e., autonomy/significance/effectiveness/belonging) fueling misbehavior
- -Offer children productive methods of getting needs met
- -*Collaborative problem-solving* can address some of autism’s core features

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Working with the Individual Child or Adolescent: Engagement and Understanding

- Create an accepting environment where the child feels respected and cared about
- Start by understanding “whole client” (thoughts, feelings, experiences, etc.); don’t emphasize problem behaviors
- Develop imagination from within client’s world; utilize multiple senses in play (i.e., sand, clay, paint); recognize that play may be less symbolic than with typical kids
- Consider puppets and miniatures to discuss people in child’s life
- Be specific with language; check in to make sure you understand and are understood
- Focus on areas of interest and competence
- Use client’s language to demonstrate empathy; consider pictures, feeling thermometers
- Validate wants/needs; identify areas of discouragement and encouragement

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Working with the Individual Child or Adolescent: Generating Behavior Change

- Set positive goals with client that fit with behavior plan; consider mapping steps towards goals visually
- Help client identify positive ways of managing feelings/getting needs met
- Identify/encourage positive behaviors and strengths
- In addressing negative behaviors, make sure legitimate wants and needs are validated
- Consider using visuals/drawing to develop ability to break down problems and cut down on black and white thinking
- Consider role plays, social stories, Comic Strip conversations to build skills
- Some ideas/schemas may be far more entrenched than with other kids

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Strengthening the family

- Assist family in dealing with stress and in managing feelings about disability and other issues; attend to different opinions, experiences, meaning attributions
- Make sure family is supported and informed; help it navigate relationships with extended family, community and navigate medical, educational and mental health/social service systems
- Assess the health/functioning of individuals, relationships, and sub-systems; look to strengthen as needed
- Look for power/workload imbalances, unhealthy alliances, unhealthy coalitions; look to open up new possibilities via talk and play sessions
- Attend to individuals, sub-systems, relationships as needed; for instance, consider parent sessions with child without disability to help child feel heard and understood.
- Look for ways for family as a whole to relax and enjoy selves. Encourage family play within session. Consider helping family plan contained, short activities/outings

A Person in Environment Approach to the Autism Spectrum Disorders in Children and Adolescents

Conclusion: the Person-in-Environment Approach

- Have a solid understanding of autism, supports and resources, and effects on individual and family.
- Prioritize empathy and understanding for child's perspective and perspective of each family member; be sensitive to peoples' perception of being judged; watch out for "pat advice"
- Attend to practical concerns: resource/time demands ,behavior management
- Empower family as Treatment Manager and advocate
- Address family's relationship to extended family/community, make sure family is as supported as possible
- Generate understanding of feelings/perspective/needs of each individual and each family relationship
- Looks to improve family functioning by addressing particular family relationships and subsystems and the family as a whole

The greater order, understanding, knowledge and skills that the child and family gain through the treatment will benefit the child's development and the family's ability to assist the child and meet everyone's needs through the Life Cycle

Bibliography

- Bromfield, Richard (2010) Doing Therapy with Children and Adolescents with Asperger Syndrome, New Jersey: Guilford
- Exkorn, Karen The Autism Sourcebook Harper Collins: 2005
- Greene, Ross W. The Explosive Child Harper Collins: 2005
- Greene and Kochbar-Bryant Pathways to Successful Transition for Youth With Disabilities Pearson Education: 2003
- Janzen, J. E. (1996). Understanding the Nature of Autism: A Practical Guide. San Antonio, TX: Therapy Skill Builders.
- Ozonoff, Et. Al. A Parent's Guide to Asperger Syndrome and High-Functioning Autism Guilford Press:2002
- Marsh, Diane A Family Focused Approach to Serious Mental Illness, Professional Resources Press: 2001
- Mufson Et. Al. Interpersonal Therapy for Depressed Adolescents Guilford Press: 2004
- O'Brien and Daggett Beyond The Autism Diagnosis: A Professional's Guide to Helping Families Paul H. Brookes Publishing: 2006
- Paxton and Estay (2007) Counselling People on the Autism Spectrum: A Practical Manual Philadelphia: Kingsley
- Seligman and Darling Ordinary Families, Special Children: A Systems Approach to Childhood Disability Guilford Press: 1997
- Walsh, Froma Strengthening Family Resilience Guilford Press: 2006