


**From Compliance to  
Excellence:**  
Creating Standards of Practice  
that Drive Program Development

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**ASD Roadmaps**

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**Disclosures**

- I might receive book and other royalties related to this topic
- As a consultant, I might benefit from the interest generated by this topic
- I have no other conflicts of interest




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**My Objectives Today**

- My goal is for you to
  - List sources and offer examples of clear practice standards relevant to initial evaluation and behavior support
  - Describe 3 ways that clear practice standards can drive improvements in service delivery
  - Illustrate how standards can increase parent engagement
  - Demonstrate why standards are essential to program replication




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**Autism Services Across America**

- Advocates & leaders
  - May not build on programs developed elsewhere
  - May lack time & experience to develop long-term plans
- This book provides
  - Background to support comprehensive planning
  - Examples of innovative state/federal programs




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**BACKGROUND**

Overview of the problem

- Quality is often evaluated relative to different kinds of "Best Practices"
- But adhering to these standards is often complex and frustrating
  - Even when failure to comply may result in a due process or other legal action, leaders panic at the prospect of being reviewed
- Goal: how to structure program development around practice standards
  - Use examples from assessment and behavior support.

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**THE IDEAL PRACTICE STANDARD**

Basis, Sources, and Products

Critical Need	Mandate/Role	Measurable goal
<b>Addresses</b>		
Strategic Plans	Budget/Insurance	Agency Policies
<b>Product</b>		
↑	↑	↑
Research Reviews	Practice Guidelines	Laws/Regulations
<b>Source</b>		
↑	↑	↑
Scientific <i>Societal Values?</i>	Legal <b>Basis</b>	Ethical <i>Cost?</i>

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**THE IDEAL PRACTICE STANDARD**  
Example: Early Identification

- Broad goal: Parents concerned about ASD get diagnosis within 4 months
- Sub-goal: Primary care practitioners (PCPs) will
  - Screen all children at 18-24 months of age for risk of ASD
  - using a test specifically validated for this purpose.



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**THE IDEAL PRACTICE STANDARD**  
Example: Early Identification

- Sub-goal: All child care professionals will screen children
  - Identified with a condition that co-occurs with, is related to, or is confused with ASD
  - using a test specifically validated for this purpose.



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**THE IDEAL PRACTICE STANDARD**  
Example: Early Identification

- Sub-goal: For a screen positive, professional will
  - Provide peer reviewed and/or consensus-developed ASD materials,
  - Immediately refer the child to EI services for a comprehensive ASD evaluation and an audiologic evaluation.



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**THE IDEAL PRACTICE STANDARD**

Example: Behavior Support Goal

- Trained professionals will promptly develop and monitor plans,
- In collaboration with caregivers,
- Coordinated across home, school, and community settings
- To address any behavior that jeopardizes the health and well-being of the child or those around him

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**THE IDEAL PRACTICE STANDARD**

Example: Behavior Support Subgoal

- For any problem behavior limiting the child's capacity to learn or access to community integration or family support, a behavior support plan must
  - Be implemented within 14 days and reviewed monthly
  - Under the leadership of a behavior specialist with specific training in ASD

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**THE IDEAL PRACTICE STANDARD**

Example: Behavior Support Subgoal

- For behaviors that risk or result in significant harm or restrictive procedures,
  - Safeguards are implemented immediately,
  - A preliminary plan developed within 24 hours,
  - Reviewed by the team within 7 days, and
  - Subject to independent, expert monitoring.

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**THE IDEAL PRACTICE STANDARD**  
Example: Behavior Support Subgoal

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- All behavior support plans will
  - Be based on a functional behavioral assessment
  - Prioritize positive, preventative, and evidence-based practices
  - Be implemented with personnel specifically trained in ASD and behavior support

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**CASE STUDIES**  
Why stories and not just data?

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- Putting a face to these challenges
  - Helps people to begin to relate to the concerns of families living with ASD
  - Makes practitioners more accountable to their clients/students/constituents
- Telling this as a story shows the
  - Multiplicative effect of simple barriers in undermining even the best practice standards
  - Different perspectives of people with ASD, caregivers, and those trying to help them

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**ENRIQUE'S STORY**  
Screening and Identification

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- Hispanic family, speaks little English, lives in a rural region
- Parent's Initial Concern: 18 months
- Referral to EI: 27 months
- Initiation of Generic EI: 30 months
- Transition to Generic Special Education: 36 months
- ASD Screening: ?
- ASD Diagnosis: 48 months

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**ENRIQUE'S STORY: IDENTIFICATION**  
How it fell short of the standard

- Parents did not express concerns
  - Are there language/culture barriers
- PCP did not screen all patients
  - Was he trained? Appropriately reimbursed? Confident in a positive outcome?
- EI team did not screen all children
  - Is there a screener specifically validated for this purpose?

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**ENRIQUE'S STORY: IDENTIFICATION**  
How it fell short of the standard

- Once at risk, neither PCP nor school-based team provided ASD materials
  - Were translated materials available?
- He was not referred for an audiologic evaluation
  - Were programs equipped for the number needing screening?
- He did not get a diagnosis in 4 months
- No one person or agency can be blamed: A network breakdown needs a network solution

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**ENRIQUE'S STORY: IDENTIFICATION**  
How could standards help?

- *Re-orient individual treatment priorities* by identifying screening as an important activity
- *Drive applied researchers to develop specific assessment protocols*, like how screening cut-offs are interpreted for to children with developmental delays
- *Set training goals for professionals*, like creating online training in ASD screening for all professionals, eligible for CEUs

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**ENRIQUE'S STORY: IDENTIFICATION**  
How else could standards help?

- *Support funding for critical interventions* by ensuring that appropriate time is allotted and activities reimbursed
- *Define an agency's mandate and policies*, by compelling agencies to support referrals for diagnostic evaluations
- *Establish system-wide goals for building capacity*, by evaluating barriers and delays to identify areas of need

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**ENRIQUE'S STORY: IDENTIFICATION**  
How else could standards help?

- *Focus oversight*, by collecting data on proportion screened or proportion missed
- *Promote cross-agency collaboration*, collective ownership of barriers and gaps
- *Inform programs to educate and engage caregivers*, like translating / disseminating Learn the Signs Act Early Materials

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**ENRIQUE'S STORY: IDENTIFICATION**  
Sources and Products

<u>Strategic Plans</u> <i>Goals re training, system outcomes</i>	<u>Budget/Insurance</u> <i>Reimbursement Levels</i>	<u>Agency Policies</u> <i>Referrals for DX Evaluation</i>
<b>Product</b>		
<u>Research Reviews</u> <i>Screening / DX instruments</i>	<u>Practice Guidelines</u> <i>AAP</i>	<u>Laws/Regulations</u> <i>IEPs / IFSPs timelines</i>
<b>Source</b>		

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**JOE'S STORY: BEHAVIOR SUPPORT**  
Home & School

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- Single parent (Jill) with 17 year old son with aggression (AGG)
- Family/Community: Limited support; AGG limits Joe's access to community activities
- School: School does FBA but
  - Focuses on immediate antecedents, misses sleep problems and need for home support
  - Relies on 1:1 support to keep Joe engaged, block minor AGG, restrict access to peers
  - Teacher emphasizes sensory diet not ABA
  - Offers little support in the summer



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**OCALICON 2013**  
**JOE'S STORY: BEHAVIOR SUPPORT**  
Physical/Mental Health

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- Physical Health: Joe's pediatrician
  - Tries to address chronic sleep problems
  - Is Jill the problem? She cancels many appts
  - Consults with neurologist to control seizures & AGG with medication
- Behavioral Health: BHRS Agency
  - Did not coordinate with school
  - Withdrew support "baseline" reached



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**JOE'S STORY: BEHAVIOR SUPPORT**  
Crisis Response

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- Broke nose during failed attempt at restraint
- 12 hour wait in ER while nurses struggled to manage him, until he was formally admitted
- No specialized in-patient treatment program available, and so Jill took Joe home
- Joe stayed home, suspended from school.
- State policies discouraged out-of-state treatment options



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**JOE'S STORY: BEHAVIOR SUPPORT**  
How the plan fell short of standards

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- Was not promptly developed and monitored by trained professionals (at school)
- Was not in full collaboration with Jill (her need and priorities ignored)
- Was not coordinated across home, school, community settings
- Did not address all behavior threatening child's health and well-being



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**JOE'S STORY: BEHAVIOR SUPPORT**  
How intervention fell short of standards

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- Basic behavior support
  - Did not prioritize positive, preventative, and evidence-based practices?
  - Was not implemented with personnel trained in ASD and behavior support
- Response to severe behaviors
  - Safeguards were not quickly implemented
  - A preliminary plan was not developed quickly
  - Was not subject to independent, expert monitoring



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**JOE'S STORY: BEHAVIOR SUPPORT**  
Can we just blame individuals?

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- Why can't Jill provide more support?
  - Professionals don't understand burdens of caregiving
- Why can't the school manage his behavior?
  - May lack funding and training
- Doesn't he just need a better medication?
  - Not always coordinated with other interventions
- Paralyzed service system missed many chances to prevent Joe's crisis



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**JOE'S STORY: BEHAVIOR SUPPORT**  
How could standards help?

- *Re-orient individual treatment priorities*, like prioritizing factors like sleep when these exacerbate behavior
- *Drive applied researchers to develop specific protocols*, like behavioral and pharmacological interventions
- *Set training goals*, like more standardized FBA, EBP for teachers, parent burden



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**JOE'S STORY: BEHAVIOR SUPPORT**  
How else could standards help?

- *Support funding for critical interventions*, including crisis/in-patient programs specialized in ASD/DD
- *Define an agency's mandate and policies*, like accommodations in doctor's office and ER; use of restraint in schools
- *Establish system-wide goals for building capacity*, like residential placements



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**OCALICON 2013**  
**JOE'S STORY: BEHAVIOR SUPPORT**  
How else could standards help?

- *Focus oversight*, like specific review when behaviors require 1:1 support OR result in injury, restrictive measures
- *Promote cross-agency collaboration*, like requiring coordination of behavior plans across home, school, and community
- *Inform programs to educate and engage caregivers*, like drawing of parent toolkits to help with sleep



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**JOE'S STORY: BEHAVIOR SUPPORT**  
Sources and Products

<u>Strategic Plans</u> <i>ASD council - system outcomes</i>	<u>Budget/Insurance</u> <i>Definition of behavioral baseline</i>	<u>Agency Policies</u> <i>Out of state placement</i>
<b>Specific Product</b>		
↑	↑	↑
<u>Research Reviews</u> <i>Behavioral intervention protocols</i>	<u>Practice Guidelines</u> <i>Accommodations for ER &amp; PCP office</i>	<u>Laws/Regulations</u> <i>Use of restraint</i>
<b>Source</b>		




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**FINAL THOUGHTS**  
Oversight

- Oversight for key processes is critical, but who does it? When? How
- Those regulated are often suspicious of impingement on clinical judgment
- For those regulating
  - Are they clinicians or administrators?
  - Too easy to focus on paperwork
- View this as a partnership with shared goals
  - Defining quality, promoting excellence
  - Identifying training needs




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**FINAL THOUGHTS**  
Advocacy

- The development of specific standards and policies is a natural step in translating strategic planning goals into action
  - Advocates who anticipate this step will make their goals more concrete
  - Opportunity for agencies and providers to describe barriers and enlist the support of advocates in overcoming them




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**FINAL THOUGHTS**  
Replication

- Many successful programs cannot define what makes them great
  - May focus on broad / general factors, funding, personnel
- Internal practice standards provide invaluable guidance to new programs
  - What kinds of training is needed?
  - What personnel and resources are needed to construct an individual treatment plan
  - How do you set overall program goals?

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**FINAL THOUGHTS**  
Inter-Agency Collaboration

- Standards of practice that frame goals in terms of child needs can help agencies share responsibilities for gaps
  - For Agency leaders, from “I cannot” to “We should”
- A chance for agencies to identify & address specific barriers in collaboration
- May foster general improvements in communication, decrease distrust

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