

Science and Soul: Our Quest to Implement PBS with Integrity in a State-Wide Autism Program

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Overview of Our Presentation

- Description of the agency
- The FFPBS model
- Concerns and challenges
- Integrating research and practice

WV AUTISM TRAINING CENTER

- Legislatively mandated in 1984
- Housed at Marshall University
- 2,200 registered families

Our Mission: WV ATC provides support to individuals with autism spectrum disorders as they pursue a life of quality



Some History: Services in the Late 80's & Early 90's

- Traditional Consulting Services
 - Each Trainer assigned about 50 families
 - Provided services on an as-needed basis
 - Assessment of training needs and development of a plan for others to implement - short term training for those plans
 - Short-term support (fix)
 - Tended to respond to crisis situations



If you do not change, you can become extinct.

“Who Moved My Cheese?” by Spencer Johnson, M.D.

The Path to Change



The Year was 1995

Opportunity to develop, implement and evaluate a PBS model of service delivery to families of children with ASDs through a grant from the Centers for Disease Control

The Family Focus PBS (FFPBS) Model was piloted with 9 families.

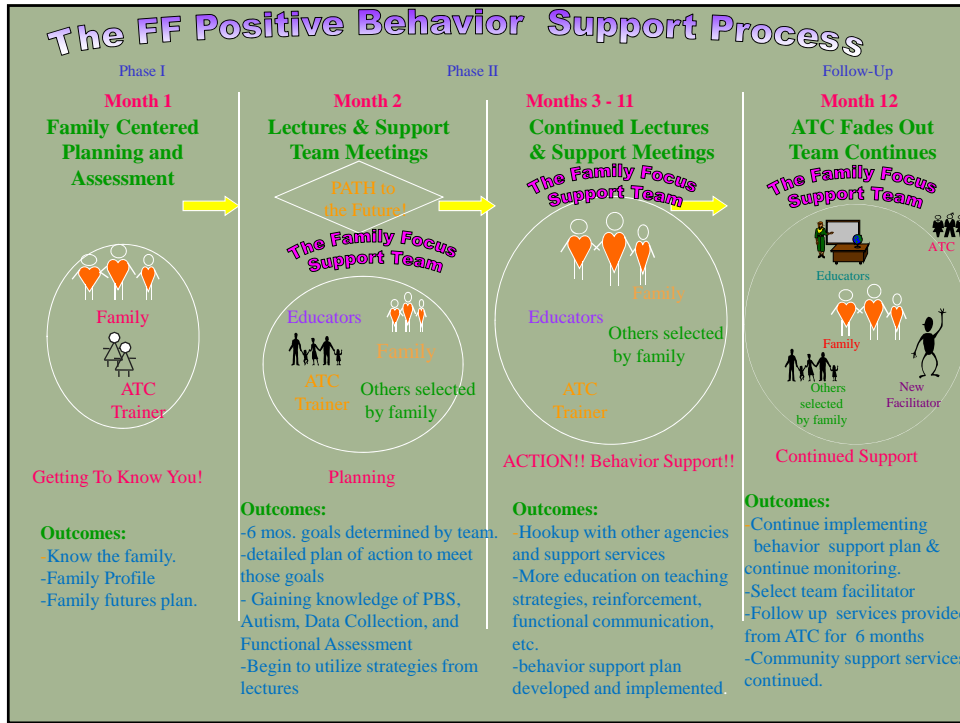
Since 1995, we have provided FFPBS to over 700 families statewide

ALL AGES
53 of 55 Counties

Family Focus Positive Behavior Support

Key Elements:

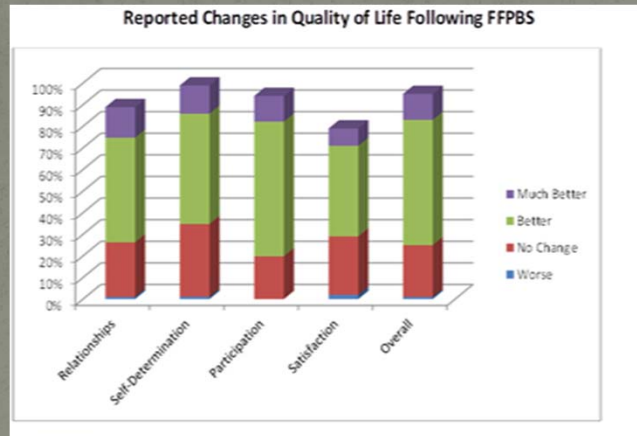
- Teamwork
- Person-Centered Planning
- Data-Driven Decision Making
- Functional Assessment
- Proactive Strategies
- PBS Plan Development
- Meaningful Outcomes



Evaluation

- Over the years we have collected data on
 - Individual targeted behaviors
 - Parenting Stress Index
 - Personal family stressors
 - Satisfaction with the process
 - Changes in Quality of Life

Quality of Life Data for Group 20



Examples of Family Focus Positive Behavior Support Quality of Life Outcomes

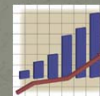
- An 8 year old girl with multiple behavior challenges was frequently sent home from school. After receiving PBS last year, she has not been sent home and received the student of the month award this year!
- A 10 year old male diagnosed with autism went to see his first movie in a theater and mom reported it was a very positive experience and that they will be going again in the future. This was an activity that the family initially thought was impossible but had a successful outing after much discussion and the implementation of a social story.
- A 17 year old high school junior with an Asperger diagnosis applied for a grant for the local genealogy society and was awarded a check for \$300.00 from the Honoring Our Ancestors Program.

“Smell the cheese often”

CHALLENGES, CONCERNS & CHANGES

Family Focus Positive Behavior Support Concerns :

- Time Constraints
- Participation & Commitment
- Team Effectiveness
- PBS Process & Materials
- Technology
- Evaluation and Research



Family Focus Positive Behavior Support Changes:

- **Refine Protocol**
- **Restructure Training**
- **Maximize Relevance**
- **Improve Buy-In**
- **Incorporate Technology**
- **Expand Evaluation & Research**

Family Focus Positive Behavior Support Timelines:

Month	Activity	Length
AUG	Meet N Greet w/ family	2 hrs.
AUG	Family Frames w/ family	2 hrs.
SEP	1 - Intro to PBS w/team	1.5 hrs.
SEP	2 - Planning (PATH)	2.5 hrs.
OCT	3 - Getting Started (Tracking Behavior)	1.5 hrs.
NOV	4 - All About Behavior (Functional Assessment)	1.5 hrs.
DEC	5 - Building Support (PBS Plan)	1.5 hrs.
JAN	6 - Working Together (Implement)	1.5 hrs.
FEB	7 - Did We Get it Right? (Evaluate & Monitor)	1.5 hrs.
MAR	8 - Planning for Change (Transitions)	1.5 hrs.
APR	9 - Follow-up (Family & Team)	2 hrs.
	As scheduled	
	Special Topics Trainings	2 hrs.

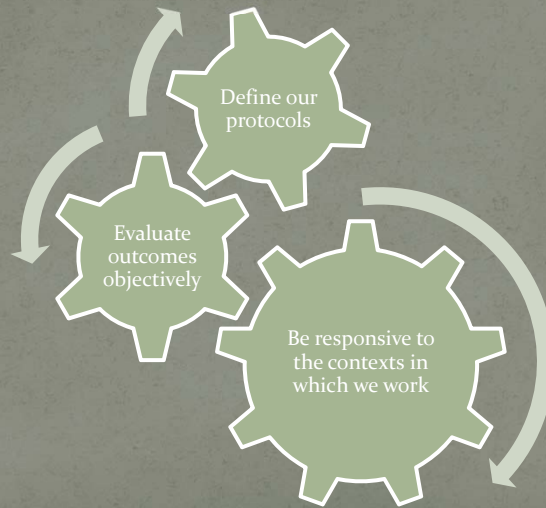
Issues and Challenges

- **Logistical Challenges**
 - Geographical, cultural challenges
 - Challenges with expectations, communication, and technology
 - Working with systems to maintain integrity and deliver content with reduced time and increased familiarity with FFPBS

Issues and Challenges

- **Challenges with Data**
 - Designing a data collection system that informed us about problem behavior, family/community dynamics, and program effectiveness in an all-in-one style
 - Obtaining consistent data for a reliable assessment of outcomes and an effective analysis of our program within a diverse population
 - Using data to improve service delivery and effectiveness while avoiding a disruption of service provision

Our Goals in PBS



Standardize Protocols (while retaining individualization)

- Clarify essential components of assessment and intervention, as well as sequence of activities
- Establish timelines - frequency of contacts, duration of intervention
- Assess fidelity to the model (e.g., through checklists, plan reviews)

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Evaluate Outcomes (Efficiently and Effectively)

- Measure what is important
 - changes in behavior (behavior rating)
 - improvements in quality of life
 - other (e.g., satisfaction, stress)
- Measure outcomes in multiple ways and at multiple levels
 - self-report and direct observation
 - group vs. individual outcomes

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	Description	Respondents	Administration
Demographic and Support/Service Questionnaire	Interview regarding characteristics of the focus person/family, living and educational circumstances, and services or assistance being received	Primary Caregiver	Phone interview Pre-administration, updated following intervention
Quality of Life Questionnaire	22-item self-report measure assessing quality of person's community involvement, relationships, and happiness.	Individual* Parent(s) Teacher/Employer Other support provider	Pre/post/follow-up; Reliability assessed per item within one category on Likert scale
Behavior Rating Scale	Rating/estimate of frequency for common behavior problems and adaptive skills	Same as above	Pre/post/follow-up; Reliability assessed across raters for exact comparison
Direct Observation	Data collection probes within target routines for 1-3 behaviors of concern and adaptive behaviors	Parent(s) Teacher/Employer PBS Trainer	Simultaneous recording using frequency count or time sampling
Questionnaire on Resources and Stress	66-item QRS assessing parent and family problems, pessimism, physical incapacity	Parent(s)	Pre/post/follow-up; Interrater reliability only if two parents respond
Satisfaction Rating	23-item questionnaire, +2 open-ended items, evaluating satisfaction, outcomes and service delivery	All participants	Post only; multiple team members respond

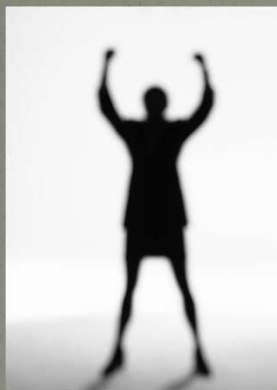
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Be Responsive to Contexts

- Insure that the protocol fits the needs of consumers and that assessment tools are reasonable and feasible
- Use data to problem-solve at multiple levels
 - Why was this particular team successful?
 - Why are there differences across participants?
 - What practices make our work more effective?
 - What changes can we make to improve the program?

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In Closing...



- Questions?

- Barbara Becker-Cottrill
<http://www.marshall.edu/atc/>

