Developing a social problem solving program with the input of adults with intellectual disabilities and their staff



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Presenter disclosures

Sarah Ailey No relationships to disclose



Purpose

 Discuss experience of involving adults with intellectual disabilities (ID) and their staff in modifying and tailoring an evidence-based social problem-solving program so that it is acceptable and useful for them.



Learning objectives

- Discuss use of cognitive interviews among individuals with ID and their staff as part of tailoring a social problem-solving program to meet their needs
- Discuss overall process of tailoring the social problem-solving program



Background

- ID affects 1-3% of population
- Over 500,000 live in community residential facilities
- Number expected to grow with aging and deaths of family caregivers
- 75% of individuals with ID in residential facilities live in small group homes



Aggressive/challenging behaviors (A/CBs)

- Residential care can exacerbate already elevated rates (45-60%) A/CBs
- A/CB rates in group homes > in family homes*
- A/CBs major reason psychoactive drugs** with high use rate in group homes (20%-50%)**
- A/CBs common reason ED visits, hospitalizations
- Serious consequences -more restrictive environments, arrests
- PUBLIC HEALTH PROBLEM

*Deb, Thomas, & Bright, 2001; ** Lunsky & Palucka, 2004: *** (Deb & Fraser, 2004).



Group homes

- Residents unknown to each other
- Staff minimal training, high school education*
- A/CBs create dynamics that increase problems**
- Staff don't know how to respond & fear affects***
- Staff often reinforce A/CBs with attention****
- Both groups ill-equipped to problem-solve and ward off A/CBs.

Hewitt et al., 2004; Wiltz**(Warren, Newsome, & Roe, 2004; Wiltz & Reiss, 2003)*** (Rose & Cleary, 2007; Whittington & Burns, 2005).. **** (Hundert, Walton-Allen, Vasdev, Cope, & Summers, 2003).



Social problem-solving

- Cognitive and behavioral activities
 - understand problems
 - cope with or find solutions
- Includes
 - Problem-solving orientation
 - positive and negative
 - Problem-solving style
 - impulsive/careless, avoidant and rational
- Tools include
 - Externalize problems

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- Stop and slow down (in order to) think and act
- Rational style Define, Alternatives, Predict, Try out

Social problem-solving in group homes*

- Purpose to modify and tailor an existing research-based SPS program** for individuals with ID and their residential staff
- Work preliminary to delivering SPS program in group homes as a health intervention.
- * Funded by Rush University College of Nursing #31202
- ** D'Zurilla & Nezu, 2007



Design

- Input from supervisory staff responsible for behavior programs for individuals with ID
- Cognitive interviews with individuals with ID and residential staff
- Pilot of program in two group homes



Advisory Group - Supervisory staff

- Initial draft of modified program
- Made recommendations
 - Simple language
 - Sessions about an hour
 - Interactive materials and group approach
 - Important issues
 - Problems are big or little,
 - Knowing when you have problems
 - Triggers
 - Stop, slow down, and think



Cognitive interviews

- How specific groups understand, process, respond to information
- Emphasis on identifying potential breakdowns in process*
- Used for instrument design
- Also used for educational materials.**

* (Willis, 2005) **(Shafer & Lohse, 2006).



Cognitive interview methods

- Verbal probing techniques comprehension and interpretation SPS material*
- Explain materials in own words.
- Confidence in material
- Retention

*Willis, 2005;



Cognitive interview analysis

- Cross-case analysis matrix*
- Core concepts of SPS unit of analysis
- Source (individual with ID and residential staff) and verbal probing issues displayed
- Focus on finding
 - Breakdowns understanding of materials
 - Alternate examples and strategies for promoting understanding of the materials

* Based on the work of Miles and Huberman (1994) and the application of Miles and Huberman in other research (Knafl et al., 2007),



Matrix display

Modules/ Core concept	Source and Comprehension/ Interpretation probes	Information type/educational strategies probes	Retention/Confidence	Decision
Module one: • Introduction • Attitude	Individuals with ID • Gave information about themselves such as; like to cook, like camping.	Picture-card sorts useful.	Followed along with pictures	Keep picture card sorts and simplify.
 Module two: Attitude Tools to "Stop and slow down" 	 Talked about "act out" Situations when they might "act out" Strategies they use to not "act out" such as "walking away" Strategies to calm/slow down such as going to quiet place, listening to music. 	 Asked about pictures of ways they react to problems Chose pictures. For "acting out" graphic of screaming frog was liked. Pictures of ways to calm/slow down Used pictures; Gave own examples. 	Followed along with pictures Suggested pictures representing ways to calm/slow down.	 Keep and develop pictures for calm down/slow down Use fewer examples Use situations they described as problems in problem list. Use fewer examples. Can give examples after initial ones.
Module 3 • Define • Begin Alternatives	Interactive game – how tall are the other participants • In general, thought other participants taller than were. Point made problems sometimes seem bigger than really are. Own ways to describe "break it down" • Ways of picturing the concept "break it down" - motion of breaking a stick.	Asked about pictures of problems faced • Some pictures were familiar as representations of problems. Suggested other examples Asked strategies to "not get mad, get challenged" • Examples with different strategies and outcomes useful Used list possible problems; card sort of options for "break it down;" pictures strategies "not get mad, get challenged."	We asked them to identify some problems they faced • Largely interpersonal issues- Not getting along with roommate; Other clients' cursing, staring; Concerns about family, health of family members.	 Modify and simplify list of problems Add health of family members to common problems Develop other pictures such as someone "breaking a stick" Incorporate examples of strategies they would use Use fewer examples of problems. Can give own examples after initial ones.
Module 4: • Alternatives • Predict	Asked what being "challenged" by problems meant to them • Own words "Face it/Step up, Fix it." • Comment "If you don't take baby steps, then it's going to drag you down." Asked own words for ways feel if react negatively or positively to a problem. • Concept difficult. At first gave ways could react and not how feel • One said reacting well " makes me feel like a better man." • Negative feelings described were "depressed" or "sad • Other feelings they added were "respected "and "connected."	 Asked about pictures of being challenged. Suggested using ways to represent "face it/step up/ fix it" Asked about pictures of feelings. One picked pictures with "proud" and "happy" as ways might feel Other pictures suggested others. 	From the previous session: • Remembered: • Introductions - Things they liked to do Things making them special • Breaking it down Noted that strategies to get challenged were difficult.	Use their examples of consequences in Pred i c t Use feelings expressed by clients i Simplify previous list of feelin g s
Module 5: Alternatives Predict	 Asked about "brainstorming" solutions to problems Word/concept "brainstorming" difficult. Did not come up with own words With examples of "brainstorming" were able to do this. 	Asked to come up with problems and then "brainstorm" • Ways to cut down on smoking talked about. Came up with 5 strategies • How to deal with someone wanting to start a fight and how to deal with the issue of shared televisions and shows want to watch -3 to 4 strategies each.	 Able to propose multiple possibilities of dealing with problems. 	 Enhance examples of brainstorming.



Results

- Concept **Positive attitude** Own words "Step up/face it/fix it"
- Concept **Impulsive** behavior/style Own words "acting out"
 - Concept **Triggers** to impulsive behaviors difficultpictures useful, examples useful
- Concept **Avoidant** style statements problems don't go away



Results

• Concept Rational style

- Component **Define** Own words "Break it down"
- Component Alternatives
 - Word "brainstorming" difficult
 - Pictures in manual useful
 - Practicing useful



Results

- Component **Predict** (two issues)
 - Feelings handle problem well/not well
 - Pictures in manual helpful
 - Examples helpful
 - Own examples handle well feel "like a better man, connected, respected."
 - Handle Not well Feel "Sad/depressed"
 - Consequences handle problem well/not well
 - In manual phrased as "things happen"
 - Experiences of negative consequences when "act out" familiar hospitalization, loss of privileges
 - Positive consequences for handling well



Conclusions cognitive interviews individuals with ID

- Original
 - manual for facilitators
 - materials for residents and staff
- Now
 - manual for individuals with ID and staff
 - materials for facilitators
- Cognitive Interviews assisted
 - Simplify to concepts grasped by participants
 - Which concepts easier/more difficult
 - Alternate examples/own words
 - Multiple methods especially to reinforce more difficult concepts



Cognitive interviews residential staff

- Staff noted seen as authority figures *but*
- Role also to facilitate independence
- Delivering program enhances this role
- Suggested adding interactive powerpoint
- Specific suggestions of scenarios for examples, interactive games for beginnings of sessions, worksheets for between modules
- Expressed confidence in working with materials



Pilot of SPS in Group Homes

- Two group homes one male, one female
- More information modifying/tailoring program
 - Importance of non-emergent space and time
 - Length of program
 - Examples of problems highlighting
 - Problems for group as whole
 - Individual problems including
 - Likely to set off "acting out"
 - Likely to lead to avoidance/denial
 - Examples of impulsive, avoidant and rational problem-solving behaviors



Discussion

- Individuals with ID and residential staff can participate in tailoring health programs
- Cognitive interviews useful for obtaining input
- Matrix provided structure to analyze input
- Process provided SPS program for pilot
- Pilot program provided further input
- Adds to research on ways vulnerable populations provide input to health programs
- Next step clinical trial SPS program.



Limitations

- Small number of people involved in cognitive interviews and pilot
- All from same agencies
- Same geographic area

