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.

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
  – 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.**

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

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

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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 difficult-pictures 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