

Living Well Together: A Consumer Oriented Approach

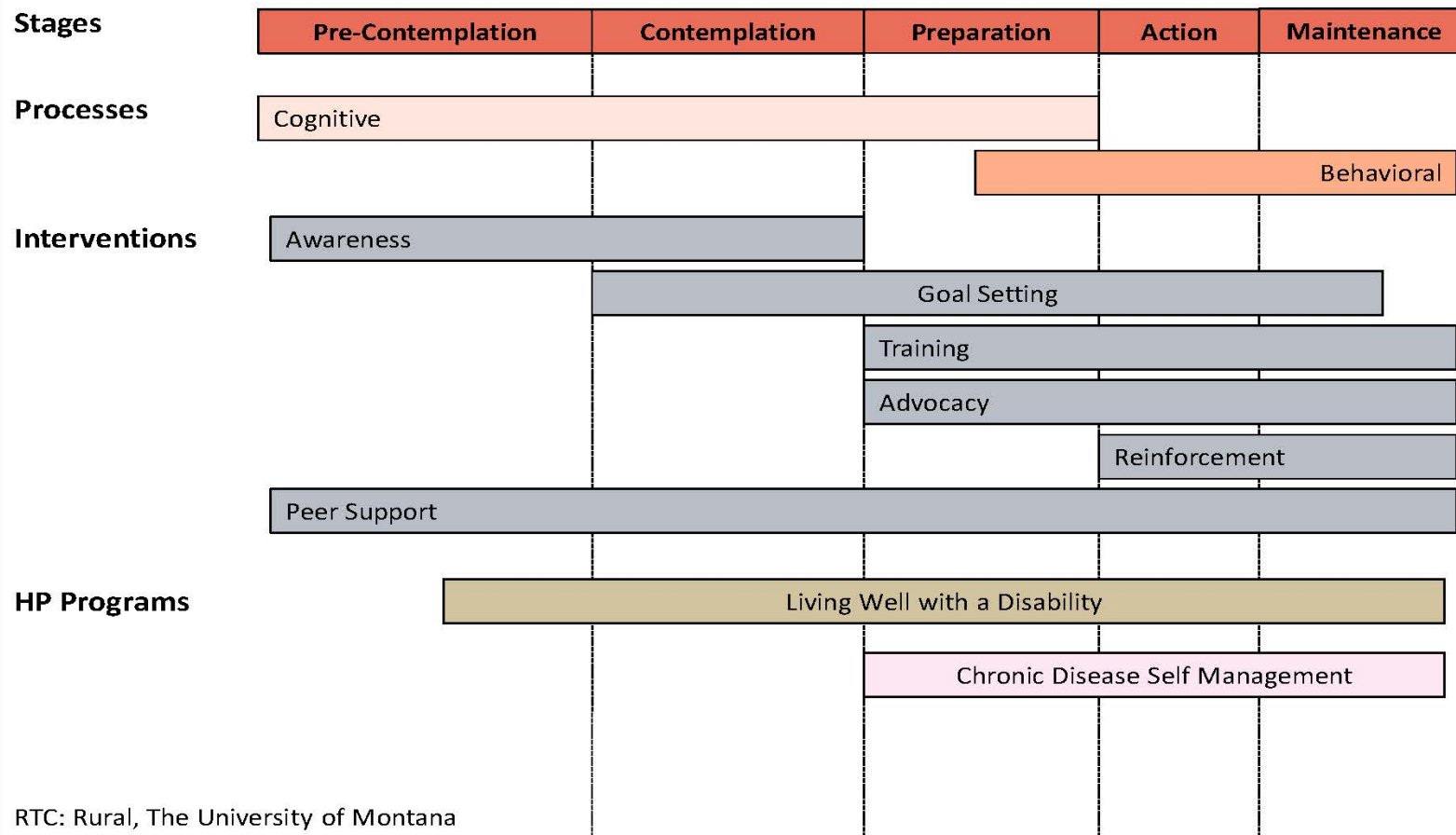


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Disability and Health Promotion



Living Well with a Disability

- *Living Well with a Disability* is an innovative, consumer-directed, goal-focused health promotion program that helps individuals develop foundations for lifestyle change (www.livingandworkingwell.org).
- Initially developed for adults with mobility impairments to improved secondary conditions (e.g. fatigue, pain, weight problems), unhealthy days, and health care utilization (Ravesloot et al., 2007).

Development of Living Well with a Disability

- Series of field trials with feedback from consumers.
- Original proposal: Individually focused, in-home, health education and support intervention.
 1. Consumers began to form groups at the end of the program.
 2. Developers began to include social support structures into the program.
 3. The Living Well with a Disability evaluation instrument was developed with consumer input to test the effectiveness of the intervention.

Implementation of Living Well with a Disability

- Final Product
 - A 10 chapter curriculum: goal setting, problem solving, attribution training, depression, communication, information seeking, nutrition, physical activity, advocacy, and maintenance (Ravesloot et al., 1998.)
 - Chapters 1-4 establish goals (pre-contemplation/contemplation)
 - Chapters 4-10 promote health behavior change (preparation, action, and maintenance).
- Delivered through community-based centers for independent living (CILs) by 2 trained facilitators over 8 weeks.

Beginnings of Living Well Together

- **Community-Based Health Needs Assessment**
(Alfonso, Walker, Gupta, Telfair, & Colquit, 2015; Colquitt et al., 2018; Walker, Alfonso, Colquitt, Weeks, & Telfair, 2016)
- **Urban versus rural comparison**
 - Parent completed surveys (N = 71)
 - Parent interviews (N = 18)
 - Service provider interviews (N = 23)

Beginnings of Living Well Together, cont.

Key Findings

- Urban and rural families had more similarities than differences
- Accessibility to services is an top issue regardless of context.
 - In urban areas this equals affordability. The services are available, but often come with a high price tag
 - In rural areas this equals affordability and accessibility to adequately trained providers

Beginnings of Living Well Together, cont.

More Key Findings

- Transitioning/Aging Out is a common theme among urban and rural parents.
 - Fear of the 'unknown' is a consistent worry among all parents.
 - Not having the structure or access to school services is a challenge.
 - Creates social and family isolation
- Service Providers aim to overcome challenges.
 - Regardless of context, service providers do what they can within their realm of capability to help families overcome barriers to access and improving adaptability.

Initial Implementation Phase 1

- Parent mentors and participants (N = 32) in a 1-1 pairing
- Parents were asked questions on level of agreement:
 - Appropriateness of material
 - Easy of curriculum
 - New information
 - Manageable workload of lesson activities
 - Ability to implement curriculum
 - Length/detail of activities

Initial Implementation Phase 1, cont.

- Weekend workshop evaluations
 - Qualitative questions (what did you like best, what did you like least, and what suggestions do you have for improvement?)
 - Field notes from evaluators
- Qualitative Portion from Facilitators Pre & Post Questionnaires
 - *What efforts can you make to stimulate parents' interest in the curriculum?*
 - *Which Activity session do you anticipate to be easy for the parents to understand and why?*
 - *Based on the information provided so far, is there something you would change about the curriculum? If so, what would it be and why?*
 - *How would you assess the sustainability of the program?*

Parent Perspectives: Phase 1

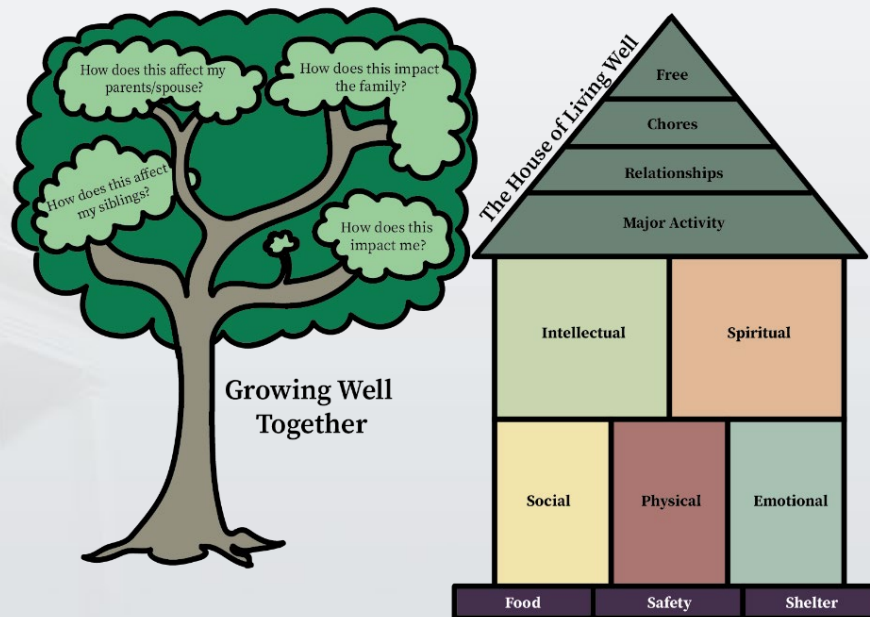
- Positive Feedback
 - The goal setting and advocacy lessons were most impactful portions of the curriculum.
 - The activities and opportunity for family engagement was appreciated.
 - The handbook was a nice addition. Having something tangible like this was noted as a benefit.
- Recommendations for Improvement
 - The timing of the lessons should be adjusted and shortened to facilitate participant engagement.
 - Additional feedback included incorporating more group activities and engagement opportunities within the lesson.

Facilitator Perspective: Phase 1

- Facilitators agreed that the most impactful portions of the curriculum were goal setting and advocacy.
 - Goal setting was easy for parents to grasp and it the activities were the most helpful in the delivery of the lessons objectives.
 - The greatest engagement happened during the advocacy lesson.
- Recommendations for Improvement
 - Facilitators found the program information and activities to be suitable for parents and adults but not for children.
 - The activities should be tailored to the reading and intellectual level of the children that this program is supposed to target.
 - Restructuring the face to face sessions to include more activities targeted for the child.

Living Well Together

- Living Well Together
 - A modified curriculum that focuses on the family.



Living Well Together, cont.

- The activity book was completely redesigned to focus on *Living Well Together*.
- More activities were designed and incorporated to increase child and parent engagement during the face to face sessions. These sessions were shortened in response to feedback from initial implementation.
- Facilitators were given 'To Do' lists to accomplish with their assigned families to help support as they reviewed new lessons.

Living Well Together, cont.

Growing Well Together

Family Session 1: Setting Goals to Live Well Together

Family Session 2: Building Support and Solving Problems

Family Session 3: Healthy Reactions

Family Session 4: Staying on Course

Family Session 5: Healthy Communication

Family Session 6: Seeking Information

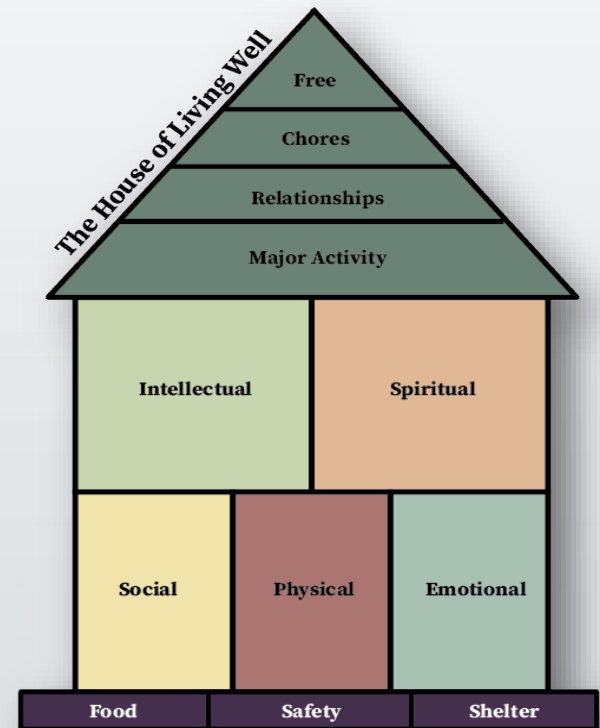
Family Session 7: Eating Well to Live Well

Family Session 8: Physical Activity

Family Session 9: Advocacy

Family Session 10: Maintenance

Appendix A: Extra Worksheets



Living Well Together, cont.

GOALS OF PHASE 2:

1. Adapt the Living Well in the Community peer led health promotion program to address the needs of families caring for adolescents living with a disability in rural, southeast Georgia.
2. Implement the adapted Living Well in the Community program in southeast Georgia.
3. Evaluate the adapted Living Well in the Community program.



Current Status of *Living Well Together*

- Program has been adapted
- First cohort (n = 10) of pilot study completed
 - Parent facilitators
 - Trained, matched, and
 - Weekend workshops
 - Data Sources
 - Pre/post surveys
 - Pre/post focus groups of the curriculum
 - Focus groups at each workshop evaluating the adapted curriculum
- Next: additional cohort to assess implementation

Key Themes of Phase 2

- Weekend workshops were helpful.
- Workbook adaptations were appropriate.
 - Parents and facilitators recommend that a parent and child handbook is created to help improve family engagement with the lessons and weekly facilitator meetings.
- Facilitator checklist and contacts were effective.

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QUESTIONS?

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