Becoming responsible: transitioning to adulthood

Young, Colleen M.

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SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

BECOMING RESPONSIBLE: TRANSITIONING TO ADULTHOOD
FACILITATING THE TRANSFER OR RESPONSIBILITY FOR DAILY LIFE TASKS FROM PARENT TO CHILD WITH DISABILITIES

by

COLLEEN M. YOUNG
B.S., Boston University, 2012
M.S.O.T., Boston University, 2014

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Approved by

Academic Mentor
________________________________________
Wendy J. Coster, Ph.D., OTR/L, FAOTA
Professor and Chair of Occupational Therapy

Academic Advisor
________________________________________
Karen Jacobs, Ed.D., CPE, OTR/L, FAOTA
Clinical Professor of Occupational Therapy
Dedication

I wish to dedicate this project to my Dad, Mom, Blake, my family, my friends and Robert Bowles.

Mom, Dad and Blake – thank you for continuing to inspire me with both your work ethic and unrelenting compassion for those around you that has undoubtedly molded me into the Occupational Therapist I am today. You never have given up on me or my dreams and I am forever indebted to you.

Rob – thank you for making me smile on the tough days and listening to me go on and on about my ideas for the project. It has been a long road and without you by my side, I am not sure how I could have done it.

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I would also like to give a special thanks to Amanda Matteo. We entered into this program together with many questions and maybe even some doubt at times, but without you walking by my side through the assignments, readings, balancing act of studying for NBCOT and applying for jobs, we made it out on the other side smiling and as closer friends.
And finally, an additional thank you to my family and friends for late night coffees and encouraging words.
Research has shown that youth with disabilities do not make as successful of a transition to adulthood as their peers without disabilities (Wells, Sandefur & Hogan, 2003; Timmons, Whitney-Thomas, McIntyre, Butterworth & Allen, 2004; Friedman, DeLucia, Holmbeck, Jandasek & Zebracki, 2009). However, a thorough literature review demonstrated promise related to evidence-based interventions seeking to increase successful transition to adulthood with this population to lessen this discrepancy between the two groups (Shogren, Wehmeyer, Palmer, Rifenbark & Little, 2015; Gharebeghy, Rassafiani & Cameron, 2015). The aim of this doctoral project was to explore the nature of this problem to better understand what has contributed to its development and to develop a solution to the problem through *Becoming Responsible: Transitioning to Adulthood*. The program is a web-based resource for parents raising youth with disabilities on how to transfer responsibility for daily life tasks from parent to child. The program is a synthesis of the Cognitive Orientation to daily Occupational Performance (CO-OP) and the Self-Determined Learning Model of Instruction (SDLMI), which were shown to be effective with a wide variety of populations (Polatajko & Mandich, 2004;
Wehmeyer, 2007). Additional information is included related to program evaluation, funding needs and dissemination plans.
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Chapter 1: Introduction

The main problem and basis of this doctoral project is the need for specific guidance to help parents transfer responsibility for managing daily life tasks to their children with disabilities. This topic was examined through a thorough literature review to identify relevant theory and existing evidence-based programs addressing this problem to develop an accessible, parent-friendly resource manual that would be made available online. The manual is intended to empower parents and increase successful self-management of daily responsibilities of the young people. Increasing independence is an important outcome for children and youth with disabilities and supporting parents to facilitate such independence is vital for healthy parent-child relationships. The desired outcome of this doctoral project is to increase parents’ confidence and knowledge of how to transfer responsibility as optimally as possible.

Research into this problem is very important as it has shown that increased independence in youth with disabilities is strongly correlated with better social-emotional wellbeing (Qin, Pomerantz & Wang 2009). Harr, Dunn & Price (2011) found that, “participation in everyday activities, such as household responsibilities, self-care, and community access, resulted in more autonomy and better self-regulation” (p. 451). Having a clear understanding of their child’s current status in self-managing daily life tasks may help parents and professionals to identify the best transition plan possible. Furthermore, parents of children with disabilities experience more stress than parents of children without disabilities (Bailey & Smith, 2000). Arming these parents with the most evidence-based resources will most likely increase their children’s independence while
also increasing social-emotional wellbeing for both parents and their children.

Occupational therapy is concerned with enabling individuals to live life to the fullest by facilitating their ability to engage in meaningful daily occupations. The profession considers all aspects of the client’s life including occupational performance and family contexts, which are main components of this project. Applying the holistic frame of mind that is foundational to the occupational therapy profession will result in a comprehensive yet flexible program to be utilized by parents in the most natural context for this population, which is the home setting.

The available research and accessible information for parents on this topic is very limited. Common popular culture books are widely available but are also limited in providing adequate guidance and evidence-based programs to parents as they approach this area of parenting a child with special needs. Parents who do not feel that they are not properly equipped with information may seek out additional, costly services. And similarly, children and youth with special needs who are given adequate opportunity to practice and assume responsibility may experience more self-efficacy and better social-emotional wellbeing. There is a rising rate of children diagnosed with developmental disabilities, which is currently one in six U.S. children. This makes increasing the available supports for families even more crucial (Goodwin, 2011).

For the purpose of this paper, transition to adulthood is used to represent the development and time period from progression of youth and adolescence to adulthood. Using the definition from the Individuals with Disabilities Education Act (IDEA), transition encompasses, “the child’s movement from school to post-school activities,
including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation” (U.S. Department of Education, 2007).

In order to provide the most comprehensive overview of the topic, the next sections of this project report will review a variety of different approaches. First, results of a wide-ranging literature review are presented. The literature review focused on research sources to develop a strong, evidence-base on which to build the program. Interviews with parents were also completed to gather first-hand parent experience regarding the transfer of responsibility. The theoretical work of Urie Bronfenbrenner is discussed as a framework for conceptualizing the need and response to the need. The knowledge gained from these sources, in conjunction with the contents of the modified version of the PEDI Responsibility Scale guided the development of a cohesive program for parents, the *Becoming Responsible* program.
Chapter 2: Theoretical and Evidence Base to Support the Proposed Project

A socio-cultural “lens” was used as the theoretical framework to understand the identified problem. The concepts of Urie Bronfenbrenner’s bioecological model provide the most thorough means of exploring the relevant contributing factors. The problem includes two related components: (1) currently, there is no parent resource on how to transfer responsibility for daily life tasks to children and youth with disabilities and (2) in general, youth with disabilities are not as successful in their transition to adulthood when compared to those without disabilities. The major propositions of Bronfenbrenner’s model will be discussed in relation to this two-part problem.

One of the major propositions of Bronfenbrenner’s bioecological model explains that human development results from an interaction between the person and his/her environment. Bronfenbrenner and Morris (2006) explain that this interaction is bidirectional, meaning, “initiatives do not come from one side only; there must be some degree of reciprocity in the exchange” (p. 798); therefore the developing person is both active and passive in his/her development. Reflecting its organismic and systems theory influences, the bioecological model categorizes the environment into different levels, known as the microsystem, mesosystem, exosystem, macrosystem and chronosystem (ranging from proximal [microsystem] to distal [chronosystem]) (Bronfenbrenner & Morris, 2006).

The current problem stems in large part to the more distal forces of the chronosystem and macrosystem in the environment. Chronosystem events exert their influence over time. For instance, the move from institutionalization to community living
for persons with disabilities shifted the roles of youth with disabilities and their parents (Brockley, 1999). Families now assumed a more significant role in preparing their children for adult life in the community. Other monumental legislative acts such as the Individuals with Disabilities Education Act (IDEA) in 1990 increased the inclusion of youth with disabilities in the local school community.

The macrosystem level is more proximal to the developing individual. Social beliefs about disability, heavily influenced by the historical events in the larger chronosystem, shifted over time in connection with several other macrosystem events. Developing bodies of knowledge contributed to this shift and therefore the development of the problem over time (i.e. medical advancements, advances in understanding of disability and knowledge of human functioning, and trends in psychology research) (Witmer, 1909; Brockley, 1999; Hexem, Bosk & Feudtner, 2011; Barone, Maddux & Synder, 1997; Dreyfus & Dreyfus, 1980).

Although these larger, more distal system levels influenced the problem, they will not be the focus of this project. More focus will be given to the microsystem, the more proximal system level, as the problem can be best understood and influenced at this level. For clarification, youth with disabilities are considered the developing individuals in this project and their parents are part of the microsystem. The interactions between youth and parents are considered proximal processes, which include persons, objects and symbols in the immediate environment. Most importantly, “to be effective [in influencing development], the interaction must occur on a fairly regular basis over extended periods of time” and must be a “progressively more complex reciprocal interaction”
Youth with disabilities may not be as successful in transition to adulthood if their parents are not equipped with the right tools to gradually help the young person take over responsibility of daily life tasks as they approach adulthood. Another major proposition of Bronfenbrenner’s bioecological model is that both the characteristics of the developing person and the environment affect, “the form, power, content and direction of the proximal processes affecting development” (p. 798). From the perspective of Bronfenbrenner’s bioecological model, it is evident that development looks different from family to family given the various environmental influences that will be present.

By combining the major propositions into one causal pathway to depict the process of change, the contribution to the problem, relevance to my project and points of possible intervention become clearer. As depicted in Figure 2.1, the bidirectional relationship between the developing child and the parents (constituting the proximal processes) initiate the course of human development. The bidirectional relationship leads to opportunities for the child to participate in various developmental activities, which are moderated by the characteristics of both the developing individual and the environment. The activities in which the developing individual participates must become increasingly complex in order for the individual to continue developing and reach the desired outcomes.
Figure 2.1: Causal Factors for Understanding Proximal Processes on Development

```
Time 1

Developing individual: child
- Interaction with parents
- Characteristics of the person
- Opportunities to participate in various developmental activities

Microsystem: Proximal Processes

Time 2

Developing Individual: older child/adolescent
- Proximal Processes: interaction with parents and other individuals (teachers, therapists, peers)
- Increasing complexity of activities

Outcomes

"generates the ability, motivation, knowledge and skill to engage in such activities both with others and on your own" (p. 797)

"increasingly become agents of their own development" (p. 797)
```
At this point, the figure progresses to Time 2, which is at an unspecified time point later in the individuals’ development. Time moderates the outcome in that the longer between the two time points, theoretically, the more complex the outcome. For example, if the child has more time between Time 1 and Time 2, they may have more opportunities to develop skills. At Time 2, the interaction between the developing individual and the proximal processes is emphasized again; however, the proximal processes now include other persons (teachers, therapists, peers). These two components (the developing individual and the proximal processes at Time 2) are partial mediators between activities of increasing complexity and the outcomes. The causal link between activities of increasing complexity and the outcomes is that as the child continues to reach goals to complete these activities he or she develops more abilities and skills.

The two outcomes that Bronfenbrenner includes in his model are that the developing individual, “generates the ability, motivation, knowledge and skill to engage in such activities both with others and on your own,” and that they “increasingly become agents of their own development” (Bronfenbrenner & Morris, 2006, p. 797). The creation of this causal pathway illustrates the congruence between Bronfenbrenner’s bioecological model and the problem. The problem lies within the proximal processes in that they are ineffective in facilitating transfer of responsibility for daily life tasks to youth with disabilities. Therefore, this population, in general, is not as successful in transitioning to adulthood as compared to youth without disabilities.

A thorough literature search was conducted to answer questions related to the proposed model detailed above to understand the experience of youth with disabilities
during transition period from high school to post-high school life. Overall the literature indicates that youth with diverse disabilities often do not make as successful of a transition to adulthood as youth without disabilities. For example, Kuriyan et al. (2012) found that a sample of adolescents with ADHD were less likely to pursue secondary education when compared to a group without ADHD. Data from the National Longitudinal Transition Study (NLTS) (sample consisting of students receiving special education services) and the National Educational Longitudinal Study (NELS) (sample consisting of cohort of eighth grade students including those with mild to moderate disabilities, but not those with severe disabilities) show a similar trend in differences between youth with disabilities and those without disabilities. A latent class analysis found that 44% of female youth and 42% of male youth with disabilities, in the NLTS sample, belonged to the “very dependent” category (unemployed, no postsecondary education, not married and no children) (Wells, Sandefur, & Hogan, 2003). There were no youth in the NELS study that fell into the “very dependent” category. Janus (2009) examined the same population at age 26 and found that the “very dependent” group continued to show poorer outcomes into adulthood (i.e. low family incomes, employment in low-level jobs, dissatisfaction with romantic relationships and high rates of illegal behavior). Dunn (1996) echoed similar findings in a study of transition services for youth with learning disabilities.

A qualitative study conducted in the Netherlands sought to understand the experience of parent caregiving raising a child with disabilities (specifically intellectual disability). Hours spent on caregiving were found to be still considerable during
adulthood, which again suggests that these individuals with disabilities had limited assumption responsibility for management of daily tasks (Haveman, Van Berkum, Reijnders & Heller, 1997).

Timmons, Whitney-Thomas, McIntyre, Butterworth & Allen (2004) found that parents felt as though the challenges in their day-to-day life, “preclude any meaningful planning on their part for their children’s future” (p. 22). These day-to-day challenges, which include, “managing everyday responsibilities and obligations” (p. 22), make it difficult for parents to develop and implement plan for their children’s future independence. Further struggles with successful transitions were found in two different studies, one of youth with Spina Bifida, which found that this population encounters difficulty with developing autonomy and independence when compared to non-disabled peers and one of youth with cerebral palsy (Friedman, DeLucia, Holmbeck, Jandasek & Zebracki, 2009; Frisch, 2013).

The second portion of this research sought to understand the relationship of parents to their children with disabilities. Considering the amount of research reporting parent stress while raising a child with a disability, Respler-Herman, Mowder, Yasik & Shamah (2012) found that more parenting stress was related to less positive parenting beliefs regarding the importance of parenting behaviors. In addition to this finding, the study determined that social support did not moderate this relationship.

Research on parenting styles with children with disabilities was difficult to locate. Although conducted in Korea, Kim & Mahoney (2004) found evidence that maternal directiveness was more common with children with disabilities when to those without
disabilities. The outcome of such a parenting style was not determined. The outcomes of this study may or may not translate to the United States given the difference in cultures. Two different studies performed by Carter Owens, Trainor, Sun & Swedeen (2009) and Carter, Lane, Cooney, Weir, Moss & Machalicek (2013) relate to importance and capacity to perform self-determination skills in a population of youth with disabilities. The first study (2009) found that parents rated their children’s ability to perform these skills significantly lower than a teacher’s appraisal of the same abilities. Parents may underestimate the capacity to perform these skills; therefore limiting opportunities to do so. The second study (2013) found that parents value self-determination skills, suggesting that a program developed to address and develop these skills would be valuable.

Saaltink, MacKinnon, Owen & Tardif-Williams (2012) investigated the role of family norms and values in decision-making opportunities for youth with intellectual disabilities (ID). Themes of protection and safety emerged from this study. Decision-making opportunities were provided to this population when the outcome was deemed to only affect the decision maker (i.e. what to wear, what to eat, etc.). The findings suggest that parents of youth with disabilities may inhibit their ability to take responsibility for daily life tasks. Strategies to practice decision-making were discussed, including guided practice and scaffolding (2012).

In terms of parents perceived relationship with their child with a disability, one cohort study found that these parents perceive the relationship as containing more conflict and less closeness when compared to children without disabilities (Totsika, Hastings, Vagenas & Emerson, 2014). In addition, more negative relationships might be related to
fewer functional skills, which may then impede typical interactions between mother and child (p. 431, 2014). Reducing conflict is an area of future research to consider from the results of this study.

A study focusing on parent relationships with a child with Fragile X syndrome reported that mothers may demonstrate over-involvement (operationalized as self-sacrifices and overprotectiveness) with adolescents with this condition. Overprotectiveness could result in fewer opportunities to assume responsibility for daily life tasks (Greenberg et al., 2012). Finally, Neece, Green & Baker (2012) found influence of parental stress on child behavior and vice versa (both serve as antecedents and consequences for one another).

Review of the literature on the influence of parents on youth with disabilities and their assumption of responsibility for daily life tasks reveals a noticeable gap. The influence of parenting styles and parental beliefs on the assumption of responsibility by youth with disabilities is unclear in the literature. Consistent with Bronfenbrenner’s mode, several studies demonstrate the bidirectional relationship between parents and youth with disabilities that has an influence on development.

The limitation of the research is the lack of a direct answer to the specific research questions in regards to parental influence. Appraisal of the research demonstrates a certain rigor, as described by the statistical analyses performed, however, several studies suffer from small sample sizes. The literature supported the proposed model it demonstrated, although to limited extent, the influence of parents on youth to different degrees and through different means. The specific focus of this project will contribute to
the knowledge base on this new topic and provide opportunities for further understanding the bidirectional relationship between parents and youth with disabilities.

The review of the literature suggests that additional support and intervention may be needed to help close the gap between youth with disabilities and youth without disabilities with respect to successful transition to adulthood. The next section of this chapter will examine research conducted on interventions that seek to address the problem using a similar theoretical framework.

**Intervention to Support Positive Transition Outcomes**

A review of interventions to increase transition outcomes identified The Self-Determination Learning Model of Instruction and Cognitive Orientation to Daily Occupational Performance interventions as potentially effective and appropriate for this context. The following evaluative summary synthesizes the results from research on the effectiveness of both of these interventions. These two interventions complement each well. Together they provide a comprehensive framework to design the most useful, versatile and accessible program for helping parents successfully transfer responsibility for daily life tasks to their adolescent. Both interventions have typically been facilitated by a special education teacher and/or occupational therapist. This project seeks to apply these interventions in the home setting. Both interventions value the role of an expert to guide the novice in the educational process; in a child’s life, the most knowledgeable person is their parent and/or caregivers.

Most of the research summarized here includes self-determination interventions that take place in the context of the school day and involve a teacher and a student with
disabilities. Most of the research on the effectiveness of self-determination interventions has been conducted with youth with intellectual disabilities. The intervention includes seven component skills that contribute to a person becoming an autonomous human being including: goal setting and attainment, choice making, self-advocacy, problem solving, decision making, and self-management (Wehmeyer, 2014). Self-determination interventions vary between multicomponent (two or more self-determination interventions) and single-component interventions targeting one aspect of self-determination (i.e. goal setting, choice making, etc.). Research has suggested that multicomponent interventions may be more effective than single-component interventions (Cobb, Lehmann, Newman-Gonchar & Alwell, 2009; Wehmeyer, 2013).

Specific components of self-determination interventions shown to be effective seek to compensate for occupational performance deficits rather than remediate underlying impairments (See Table 2.1 for Elements of Intervention). The Self-Determined Learning Model of Instruction (SDLMI) is one specific intervention that has been widely studied. This model follows three phases of instruction: Goal, Take Action and Adjust Goal or Plan, while providing worksheets for students to follow with support of the educational provider. Each phase, “presents a problem to be solved by the student” and “the student solves each problem by posing and answering a series of four questions per phase that students learn, modify to make their own, and apply to reach self-selected goals” (Wehmeyer, 2007, p. 123). Goals typically set within the SDLMI are educational, as it has been mostly implemented in the school setting. For example, students are prompted to first consider what class he/she wants to improve in, such as English, math
The students then consider four questions that guide them to develop an appropriate plan to attain the goal (Wehmeyer, 2007). The four questions are: What do I want to learn? What do I know about it now? What must change for me to learn what I don’t know? What can I do to make this happen? By answering the series of questions, students learn to create a means-ends chain, which reflects the core components of problem-solving skills: identifying the problem, current status in relation to the goal, identifying barriers to reaching the goal and developing a plan to overcome the barriers and to meet the goal (Wehmeyer, 2007).

Table 2.1: Elements of Intervention

<table>
<thead>
<tr>
<th>Element of Intervention</th>
<th>Research Study</th>
<th>Type of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal setting and attainment (coaching in youth-directed)</td>
<td>Shogren et al. (2012)</td>
<td>Cluster or group-randomized trial control, large sample size (n=312)</td>
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<tr>
<td></td>
<td>Wehmeyer et al. (2012)</td>
<td>Group randomized, modified equivalent control group, time series (n = 312)</td>
</tr>
<tr>
<td></td>
<td>Mazzoti et al. (2013)</td>
<td>Multiple probe across participants design (n=4)</td>
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<tr>
<td></td>
<td>Powers et al. (2012)</td>
<td>Longitudinal, randomized study (n = 29)</td>
</tr>
<tr>
<td></td>
<td>Gharebaghy et al. (2015)</td>
<td>Experimental design single case, (n=6), one disability group (ADHD), context = Iran</td>
</tr>
<tr>
<td></td>
<td>Phelan et al. (2009)</td>
<td>Single case study design, n =2 with HFA/Asperger’s syndrome</td>
</tr>
<tr>
<td>Choice making</td>
<td>Algozinne et al. (2001)</td>
<td>Meta-Analysis of research (n = 51)</td>
</tr>
<tr>
<td>Parent/caregiver involvement</td>
<td>Dawson et al. (2009)</td>
<td>Pilot study: single case study design, n =3, adults with TBI.</td>
</tr>
<tr>
<td></td>
<td>Phelan et al. (2009)</td>
<td>Single case study design, n =2 with HFA/Asperger’s syndrome.</td>
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<tr>
<td>Self-advocacy</td>
<td>Algozzine et al. (2001)</td>
<td>Meta-Analysis of research (n = 51)</td>
</tr>
<tr>
<td>Problem-solving</td>
<td>Algozzine et al. (2001)</td>
<td>Meta-Analysis of research (n = 51)</td>
</tr>
<tr>
<td></td>
<td>Hyland (2012)</td>
<td>Secondary analysis, randomized, two-group clinic based trial (phase A, n =20) &amp; randomized two group community based trial; feasibility (phase B, n =8)</td>
</tr>
<tr>
<td></td>
<td>Dawson et al. (2009)</td>
<td>Pilot study, single case study design, n=3, adults with TBI.</td>
</tr>
<tr>
<td></td>
<td>Powers et al. (2012)</td>
<td>Longitudinal, randomized study (n = 60)</td>
</tr>
<tr>
<td>Self-management</td>
<td>Mazzoti et al. (2013)</td>
<td>Multiple probe across participants design (n=4)</td>
</tr>
<tr>
<td></td>
<td>Hyland (2012)</td>
<td>Secondary analysis, randomized, two-group clinic based trial (phase A) &amp; randomized two group community based trial; feasibility (phase B)</td>
</tr>
<tr>
<td>Multicomponent interventions</td>
<td>Palmer et al. (2012)</td>
<td>Randomized trial placebo control group study (n=317)</td>
</tr>
<tr>
<td></td>
<td>Wehmeyer et al. (2013)</td>
<td>Metasynthesis (review of 7 narrative and systematic reviews)</td>
</tr>
<tr>
<td>Coaching</td>
<td>Powers et al. (2012)</td>
<td>Longitudinal, randomized study (n = 60)</td>
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</table>
There is strong research evidence supporting the effectiveness of the self-determination interventions. The research examined for this project includes multiple studies with large sample sizes, which further supports the focus on the Self-Determined Learning Model of Instruction (SDLMI) within this synthesis as larger sample sizes in a study increase the generalizability of results (Palmer, Wehmeyer, Shogren, Williams-Diehm & Soukup, 2012; Shogren, Palmer, Wehmeyer, Williams-Diehm & Little, 2012; Wehmeyer Shogren, Palmer, Williams-Diehm, Little & Boulton, 2012; Wehmeyer, Palmer, Shogren, Williams-Diehm & Soukup, 2013; Powers et al., 2012; Algozzine Browder, Karvonen, Test & Wood, 2001).

Component skills addressed in the self-determination interventions vary but a common theme in the research is the importance of goal setting. Goal setting is a primary element of self-determination interventions and research has shown its effectiveness to support goal attainment (Shogren et al., 2012; Wehmeyer et al., 2012; Mazzotti, Test & Wood, 2013; Powers et al., 2012). Within the SDLMI, the teacher supports the student in setting a student-identified goal by answering the four questions, as described above, which highlights the importance and intricacies of the goal setting process as the starting point for creating a means-end chain.

The next phases of the SDLMI are Taking Action and Adjusting Goal or Plan. There are multiple important elements that are vital to the success of these two phases. Research supports the importance of these phases to facilitate the development of self-determination. Both choice-making and self-advocacy are the most commonly addressed interventions related to self-determination skills (Algozzine et al., 2001). In addition, it
has been shown that component skills of self-determination can be learned by students with disabilities (Algozzine et al., 2001). Choice-making is vital to these two phases of the SDLMI as the student must make choices by developing the plan of action and deciding whether to continue with the plan of action or to adjust the plan. Self-advocacy is an important component of Taking Action that allows the student to demonstrate assertiveness with the planning process through the use of effective communication skills. Expanding programs to address other vital self-determination skills, such as self-evaluation and decision-making, would provide youth with disabilities stronger support and more opportunities to reach successful adult outcomes.

The SDLMI includes other elements believed to be effective in increasing self-determination. These include: problem-solving (Hyland, 2012; Powers et al., 2012 & Dawson, Gaya, Hunt, Levine & Polatajko, 2009), coaching (Powers et al., 2012) and self-management (Mazzotti et al., 2013; Hyland, 2012). Participation in self-determination interventions has been shown to increase outcomes outside of intended goals set by participants, which may demonstrate generalization of these skills to other areas of life, including independent living skills, such as paying a phone bill and making medical appointments (Powers et al., 2012).

The weakness of the research and evidence for the use of the self-determination interventions is that most interventions intend to influence many self-determination skills; therefore, it is difficult to draw definite conclusions as to what aspects of the intervention are casual agents influencing outcomes. Furthermore, all research included in this synthesis was conducted in educational settings, therefore it is unknown what effect they
might have when they are applied in the home setting with parents implementing the intervention. In addition, self-determination interventions, as currently implemented, focus on educational goal attainment as opposed to goals related to daily living skills. Another reservation with the use of this research is that the majority of programs have focused on transition age youth; however, to date, minimal research has examined the success of implementing self-determination programs across the lifespan.

As previously mentioned, multicomponent self-determination interventions, meaning the combination of SDLMI and another intervention, may be more effective in increasing self-determination in youth with disabilities (Palmer et al., 2012; Wehmeyer et al., 2013; McDougal, Evans & Baldwin, 2010; Powers et al., 2012; Cobb et al., 2009). The proposed parent program seeks to build on this research by developing a multicomponent intervention that combines the SDLMI and a second and widely researched program, the Cognitive Orientation to Daily Occupational Performance, CO-OP.

The Cognitive Orientation to Daily Occupational Performance (CO-OP) theoretical base draws from both cognitive behavioral and motor learning principles. It teaches cognitive strategies as a means to solve daily occupational performance problems and has been studied with children and adolescents with Developmental Coordination Disorder (DCD), Attention Deficit Hyperactivity Disorder (ADHD), Acquired brain injury (ABI), Autism, adult traumatic brain injury (TBI) and the adult stroke population. Participants are taught the global strategy of Goal-Plan-Do-Check, which has some similarities to SDLMI (Phelan, Steinke & Mandich, 2009) as both interventions include
goal setting and developing a plan. CO-OP has the potential to fill gaps that self-determination interventions do not address. The main difference between CO-OP and SDLMI is the use of cognitive strategies as a means to problem solve and meet goals. Guided discovery is one of the main principles on which the CO-OP intervention is based. This approach takes advantage of the therapist’s expertise and knowledge to guide the child through the process of discovering domain-specific strategies to solve occupational performance problems (Gharebaghy, Rassafiani & Cameron, 2015; Hyland, 2012; Dawson et al., 2009; Phelan et al., 2009; Polatajko, McEwen, Ryan & Baum, 2012; Missiuna et al., 2010).

Dynamic performance analysis (DPA) is another vital element of the CO-OP intervention. This aspect of intervention involves the therapist observing the child performing the task in order to assess motivation, task knowledge and performance competence (Coster & Cohn 2013). These three factors may contribute in part or whole to performance breakdowns or, in other words, where the child experiences issues with a task. Research has shown that children may be capable of conducting their own DPAs, which can facilitate further generalization of skills (Hyland, 2012; Dawson et al., 2009; Missiuna et al., 2010). Developing the ability to identify where there is a performance breakdown may facilitate the problem-solving process across various daily life tasks.

One strength of the research and evidence on the CO-OP is that the intervention has been investigated with diverse populations (DCD, ADHD, ABI, TBI, Stroke) and ages (youth and adults), which demonstrates the intervention’s versatility and accessibility. The involvement of parents and caregivers in the CO-OP intervention has
proven beneficial to maximize outcomes of the intervention (Phelan et al., 2009; Dawson et al., 2009), which provides support for having parents implement this intervention in the home setting. Engagement in the child’s natural context is also an important component of the CO-OP intervention. The theoretical model highlights the connection between the occupation (or task), the person and the environment, which is essential to understanding and optimizing occupational performance (Dawson et al., 2009; Polatajko et al., 2012). Performing an occupation in the natural, or typical, context provides more opportunities for generalization and transfer of skills.

A limitation of the research and evidence on the CO-OP intervention is that the majority of the studies cited in this synthesis had small sample sizes, with the largest including 35 participants. Caution is needed when drawing conclusions from such small sample sizes. In addition, all the studies involved an occupational therapist providing the intervention directly to the client. This program intends to bring the CO-OP intervention into the home setting to be implemented by a parent, which, to the best of our knowledge, has not been studied to date. In several studies, there was no control group, which threatens the internal validity of the studies and therefore limits the confidence when drawing conclusions from the data. (Missiuna et al., 2010; Skidmore et al., 2011; Phelan et al., 2009; Dawson et al., 2009; Gharebaghy et al., 2015). In addition, although CO-OP is supposed to take place in a natural context, many of the studies reviewed did not include this feature (Gharebaghy et al., 2015, Hyland, 2012; Phelan et al., 2009; Missiuna et al., 2010; Skidmore et al., 2011; McEwen et al., 2015).

After conducting a thorough review of the evidence on these interventions, it
seems appropriate to include both in the creation of this parent-based resource guide. These two interventions, Self-Determined Learning Model of Instruction and the Cognitive-Orientation to daily Occupational Performance, appreciate the highly individual nature of the performance difficulties of youth with disabilities, which is reflected in the client-centered nature of these interventions. At the same time, they have standardized approaches, which allows them to be replicated. The standardization of both programs increases the likelihood of successfully transitioning these interventions to the home setting for parental use. Both interventions, SDLMI and CO-OP, appreciate the role of an expert to guide the novice through problem-solving steps utilizing either the “Set a Goal, Take Action, Adjust Goal or Plan” or Goal-Plan-Do-Check strategies (See Appendix D for Evidence Table). Both interventions seek to assist the novice in developing various skills to set a goal, make a plan and evaluate performance in hopes of promoting generalization to successfully take on responsibility for daily life tasks. Supporting parents to successfully transfer responsibility for daily life tasks to their adolescents with disabilities may have a positive impact on quality of life, of both parents and youth with disabilities, and improve transition outcomes for more successful adulthood.
Chapter 3: The Proposed Program

The proposed program, *Becoming Responsible: Transitioning to Adulthood*, is a web-based resource to assist parents with the process of transferring responsibility for daily life tasks to their son or daughter with disabilities. Extensive literature review demonstrates there is a lack of evidence-based resources to guide parents in this process. In addition, this literature review identified that youth with disabilities are often less successful in their transition to adulthood compared to youth without disabilities. This program is based on the evidence-based interventions of the Cognitive Orientation to Daily Occupational Performance (CO-OP) and the Self-Determined Learning Model of Instruction (SDLMI).

Program Description

**Program goal.** Parents will successfully transfer responsibility for managing daily life tasks to their children with disabilities to promote more successful transition to adulthood.

**Program Objectives.** By the end of the program, parents will be able to:

- Help their child develop daily life goals
- Identify performance breakdowns in their child’s performance of a task
- Use guided discovery as a means to help their child develop problem-solving skills
- Increase self-determination in their child
- Reduce parent responsibility in managing daily life tasks for their child
Outcomes. Proximal outcomes include increased ability to help the child problem-solve solutions for daily life tasks, and reduce the level of responsibility a parent takes for daily life tasks as measured by the Modified PEDI Responsibility Scale. A distal outcome is that youth with disabilities will achieve more successful transition to adulthood, as measured by secondary education, employment and independent living.

Recipients. Program participants include parents of youth with disabilities.

Program Format. The program format is planned as an online web-based resource that allows parents to read material and print off worksheets and activity sheets. No information or login information is needed to access the manual. The program is designed to be flexible so that parents can decide which strategies, worksheets and activities they will implement with their child. The flexible nature of the program reflects the program's value of supporting parents to make their own decisions about how they want to make use of the program in the way they deem best for their child. Parents make the decisions regarding what strategies to use, when to use the strategies and how to use the strategies. In addition, the flexibility of the program may increase its applicability to a wide range of diagnoses, as some strategies may be more successful than others for different parent-child dyads (Gharebaghy, Rassafiani & Cameron, 2015; Hyland, 2012; Dawson, Gaya, Hunt, Levine & Polatajko, 2009; Phelan, Steinke & Mandich, 2009; Polatajko, McEwen, Ryan & Baum, 2012; McEwen et al., 2015; Missiuna et al., 2010; Skidmore, Holm, Whyte, Dew, Dawson & Becker, 2011; Wehmeyer, 2007).

On the homepage of the website parents will be oriented as to how best to interact with the materials available to them through a short introduction. It is important to include
some level of introduction for the parents to optimize their interaction with materials. This introduction will explain that some of these strategies may work well for those with intellectual disabilities while others may require meta-cognitive abilities too abstract and difficult for certain children. The combination of two different intervention approaches seeks to increase the population that the program could be helpful for (Palmer, Wehmeyer, Shogren, Williams-Diehm & Soukup, 2012; Wehmeyer, Palmer, Shogren, Williams-Diehm & Soukup, 2013; Cobb, Lehmann, Newman-Gonchar & Alwell, 2009; McDougall, Evans & Baldwin, 2010; Powers et al., 2012).

**Key Components of the Proposed Program:**

*Goal setting.* The key components of the program include a combination of elements from both the CO-OP and SDLMI interventions. The first key component to address is goal setting, which takes place in Phase 1: Goal Setting. Both interventions emphasize the importance of goal setting as the preliminary step in the problem-solving process (Polatajko & Mandich, 2004; Wehmeyer, 2007; Shogren, Palmer, Wehmeyer, Williams-Diehm & Little, 2012; Wehmeyer, Shogren, Palmer, Williams-Diehm, Little & Boulton, 2012; Mazzotti, Test & Wood, 2013; Powers et al., 2012; Phelan et al., 2009). Parents complete the modified PEDI Responsibility Scale to identify areas to focus on with their child (Appendix F). The parent completes the assessment and has a conversation with their child about goal setting and areas to work on and allows the child (to the best of their ability) to make decisions on what goals to work on (Appendix F).

*Global strategy.* The program emphasizes the importance of introducing a Type 1 Strategy, which is Goal-Plan-Do-Check (Polatajko & Mandich, 2004). Continually
stating and reinforcing the global strategy may help the child recall the steps to the process. The global strategy is best introduced soon after goal setting in Phase 1: Goal Setting, but is emphasized through all the subsequent phases including Phase 2: Plan, Phase 3: Do and Phase 4: Check. The parent can decide what is the most age appropriate and meaningful means of representing the global strategy. In the CO-OP program, the therapist uses an astronaut with the name Captain Goal-Plan-Do-Check, but the present program values the role of the parent in determining what might be more meaningful and motivating for the child (2004). How best to represent the global strategy is to be determined by the parent, which is described in the orientation to the program.

**Observation.** The next key component is having the parent observe while the child performs the identified task, which follows the principles of a dynamic performance analysis (Polatajko & Mandich, 2004). Using the Observation Worksheet (Appendix F) to assist with this analysis, the parent determines where the child encounters difficulty with the task. The observation process takes place during Phase 2: Plan.

**Guided discovery.** Guided discovery is another key component that also takes place during Phase 2: Plan. Prior to utilizing the guided discovery task, the parent may decide to utilize the Guided Discovery Worksheet in order to write down the steps of the task at hand. As the child engages in the task, the parent verbalizes the steps out loud with the goal that the child will internalize the parents’ verbalization and progress to using self-talk as the child becomes more independent with the task (Polatajko & Mandich, 2004; Gharebaghy et al., 2015; Hyland, 2012; Dawson et al., 2009; Phelan et al., 2009; Polatajko, McEwen, Ryan & Baum, 2012; Missiuna et al., 2010). Guided
discovery allows the parent to assist the child through the difficult parts of the task in order to have the child develop Type 2 Strategies, which apply to specific tasks (e.g., using a checklist when packing backpack for school to compensate for difficulty with memory). These specific strategies are called Domain Specific Strategies, but have been renamed in the program to Type 2 Strategies as a means to simplify the content to make it more accessible for parents. CO-OP includes four helpful and straightforward reminders for the parent to remember during this part of the program, which include the following: coach, don’t adjust; make it obvious; one thing at a time; and ask don’t tell (Polatajko & Mandich, 2004). Descriptions of how to best utilize these strategies are included within the program and examples can be found in Appendix F. These are vital for the parent to consider during this phase because of many parents’ have a habit of jumping in and helping when a child experiences difficulty.

**Type 2 Strategies.** Type 2 Strategies are developed through the guided discovery process using the Type 2 Worksheet (Appendix F). This worksheet helps the parents identify the strategies that may help the child complete the task successfully. Areas to attend to for potential development of Type 2 strategies include the child’s body position, attention to task, task specification/modification, supplementing task knowledge, feeling the movement, verbal motor mnemonic and verbal rote script.

**Self-instruction or Self-talk.** The self-instruction or self-talk strategy can be utilized during both Phase 2: Plan and Phase 3: Do. It is typically coupled with the guided discovery process, but can be a good strategy for the child to self-cue during sequencing and therefore, can also serve as a means to self-monitor, self-regulate and self-evaluate

**Antecedent cue regulation.** Parents may decide it is best to use antecedent cue regulation as a strategy to increase responsibility with the task. This strategy may be implemented in Phase 3: Do. This strategy seeks to make a cue more obvious so that the child initiates the next step. Picture prompts or auditory prompts could be used depending on the child’s preferred method of learning (Wehmeyer, 2007). Increasing use of high tech devices such as iPads and iPhones may make picture and/or auditory prompts more accessible and easy to use during the child’s daily routine. Use of this strategy may be helpful for different populations, but is most useful as a compensatory approach. For example, use of picture or auditory prompts may be useful for youth with intellectual disabilities (2007).

**Promote learning.** The CO-OP intervention incorporates four strategies to further promote learning of problem-solving strategies that parents can implement during Phase 3: Do (Polatajko & Mandich, 2004). The first strategy is direct teaching. Direct teaching typically involves physical assistance with the task in an attempt to supplement task knowledge. Secondly, modeling is another option, which may feel more natural to a parent. Modeling allows the parent to demonstrate the task for the child to observe. A third strategy is prompting, which takes different forms including verbal, visual and physical prompts to cue the child as to what comes next in a multi-step task. Finally, a parent could use fading, which involves the gradual removal of supports needed to complete the task (whether that be visual, verbal or physical). In addition, both internal
and external reinforcement are important factors in promoting learning. Parents typically know what motivates their child the most. Both verbal praise and visual representation of progress, such as checkmarks or stickers on a progress board, can be implemented as an additional measure of external reinforcement.

**Self-evaluation.** Phase 4: Check involves having the child identify if the plan worked and the goal has been met. Self-evaluation can promote internal reinforcement abilities (Polatajko & Mandich, 2004). Both CO-OP and SDLMI include a feedback or monitoring loop for problem-solving (Polatajko & Mandich, 2004; Wehmeyer, 2007). For example, the child can determine if the goal has been met by comparing current performance with the task and desired level of performance of the task. Facilitating the development of self-evaluation abilities is an important component of the program, so that a child can determine whether the strategy worked in reaching the desired goal without the feedback from someone else (Wehmeyer, 2007). Being able to sufficiently self-evaluate can then allow the child to experience success, which is an internal reinforcement. Having clearly defined expectations for the task assists with this process by explicitly describing what behavior, and actions are required to complete the task. Self-evaluation skills are an important sub skill of self-determination (Wehmeyer, 2007).
<table>
<thead>
<tr>
<th>Phase</th>
<th>Activities</th>
</tr>
</thead>
</table>
| 1. Goal | 1. Complete Taking Care (modified PEDI Responsibility domain)  
2. Parent identifies areas to work on with child  
3. Parent has conversation with child and child sets 2–3 goals.  
4. Complete Phase 1 Worksheet for one goal at a time. |
| 2. Plan | 1. Parent has child perform the task and observes the child while filling out the Observation Worksheet.  
2. Complete Phase 2 Worksheet.  
3. Discuss barriers or things getting in the way with child. (ROAD BLOCKS)  
4. Type 1 Strategy introduced: GOAL-PLAN-DO-CHECK. Choose a motivating image for the child.  
5. Guided discovery as child performs the task, providing cues when child encounters difficulty.  
6. Identify Type 2 Strategies using the Type 2 worksheet. |
2. Guided discovery as needed.  
3. Use the strategies of: “Coach, don’t adjust; make it obvious; one thing at a time; and ask don’t tell.”  
4. Encourage child to use self-talk.  
5. Use Type 2 strategies made during Phase 2: Plan.  
6. Promote learning via direct teaching, modeling, shaping, fading, and chaining.  
| 4. Check | 1. Complete Phase 4 Worksheet to help child determine if plan worked and goal was reached or if need to return to plan to adjust accordingly.  
2. Use visual/auditory checklist if appropriate.  
4. Encourage generalization to other tasks. |
Barriers and challenges for implementation.

The primary barrier for implementation of this program is that it is a non-interactive, stand-alone resource for the parents to use. There is limited means for feedback from the main author. Parents may have many questions regarding the program and will have limited ability to interact with the author and/or other parents using the program. Parents are encouraged to bring ideas to the professionals who work with their child at school including special education teachers and occupational therapist. Their professional input may be invaluable as parents attempt to implement this program in the home setting. Consultation with these professionals may help identify opportunities for transferring skills and generalization between the home and school setting.

Although every effort has been made to simplify and synthesize these interventions into a usable and flexible program for parents, some content may still be difficult for parents to understand and implement correctly. Furthermore, this program is only available in English and may be challenging for parents and children who are English Second Language (ESL) or non-English speaking. These limitations may impact the ability for these parents and children to fully benefit from the information being provided. And finally, at this time, this program will only be available online and requires worksheets to be printed, both of which would be challenging for those without access to computers, printing and/or the Internet.
Chapter 4: Program Evaluation

The program I seek to provide is a resource for parents of young people with special needs. The aim of the program is to help parents guide their children to take over more responsibility for managing daily life tasks by the use of step-by-step instructions and coaching techniques based on the Self-Determined Learning Model of Instruction (SDLMI) and the Cognitive Orientation to Daily Occupational Performance (CO-OP).

The context for the study (program evaluation) being proposed is for use within middle and high schools providing services to children and adolescents and additional service agencies working with this population. The program evaluation will take place in two phases. First phase will be a pilot study of the program with a small sample size from a small geographical area. The second phase will use the information gathered from the first phase to improve the program with revisions to the manual and subsequently a larger scale program implementation and evaluation will be conducted.

The following sections detail the core purpose, the scope of the evaluation, the evaluation questions, type of research design and methods and data management plan utilized in this program evaluation. In particular this program evaluation will be used to determine whether or not the intervention is providing the appropriate guidance to help parents successfully transfer more responsibility for daily life tasks to their children with special needs. In addition to evaluating this outcome, the program evaluation aims to gather information on the parents’ perspectives of the accessibility and satisfaction with the program to use for program improvement.
Core Purpose:

The core purpose of this program evaluation is both formative and summative. Both of these approaches are appropriate to use. The formative approach will take place in phase 1 and allows for gathering of information to determine program improvements. The summative approach will take place in phase 2 and allows for determining the effects of the intervention on outcomes.

Scope of Evaluation:

In order to collect comprehensive information regarding the effectiveness and overall satisfaction with the program, both quantitative and qualitative methods will be utilized. The program evaluation has been separated into two phases, first of which will be completed in year one of implementation, and second of which will be implemented in year two. Both phases will incorporate pre- and post-test measurements.

The first phase of the program evaluation will involve the recruitment of a small sample size (n = 5–10) from a local and private special education school. Parents recruited will agree to complete written assessment to be returned by mailed to the main author and to participate in telephone interview. Parents will be mailed the Pediatric Evaluation of Disability Index (PEDI) Responsibility domain prior to the start of utilizing the program for completion at the beginning and after 6-months of interaction with the program. Telephone interviews containing open-ended questions will be conducted at 6-month mark to gain qualitative information regarding overall satisfaction with program, what parents liked or disliked, most valuable and least valuable aspects, and most difficult strategies. Feedback from both methods of data collection will be utilized for
program improvement prior larger scale program implementation and program evaluation.

The second phase of the program evaluation will involve recruiting a large sample size \((n = 30)\) from a larger geographical area. Parents will be recruited through Easter Seals Child Development Centers. Processes will take a similar approach as in first phase; including the mailing of PEDI Responsibility domain for completion at beginning, at 6-months and at 12-months. For qualitative data, parents will be prompted to complete a survey, at 12-months, containing statements to rate on 5-point Likert scale related to overall satisfaction with program, what parents liked or disliked, the most valuable and least valuable aspects, and the most difficult strategies to implement as well as three open ended questions.

**Table 4.1: Evaluation Questions:**

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Evaluation Questions</th>
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</thead>
<tbody>
<tr>
<td>Potential clients (parents)</td>
<td>Did my child gain more responsibility after participating in this program? [Was I able to effectively transfer responsibility of daily life tasks to my child? [Was I satisfied with this program? [Was I able to successfully access the content of the program? [Did I understand the content of the program? [Was I able to apply the information? [How does this program compare to other services received or programs I have participated in with my child?</td>
</tr>
<tr>
<td>Program managers (author and academic advisor)</td>
<td>Is the step-wise fashion of the program effective in guiding parents? [Are parents satisfied with the program? [Were parents able to effectively transfer responsibility for daily life tasks to their children with disabilities? [Was the information accessible and useful to the parents?</td>
</tr>
<tr>
<td>Service agencies, organizations, etc.</td>
<td>How will our program participants benefit from using this program? [How will this program benefit our organization? [Were participants satisfied with the program? [How does this program align with our own mission?</td>
</tr>
</tbody>
</table>
Data Management Plan:

As previously mentioned, repeat assessments with the modified Responsibility Scale can be used to evaluate change. For the pilot phase, the Responsibility Scale will be completed once pre-program and again 6-months later. For the second phase, scores will be obtained at the beginning of the study, 6-months into using the program and at 12-months follow-up to evaluate long term outcomes. In both phases, the data from the modified Responsibility Scale will be entered into an Excel spreadsheet stored on a designated computer and data backup will be provided through a secure cloud system. Data will be stored on a secure database on the main author’s computer with an additional external harddrive for backup (which would be routinely updated on a weekly basis). This database would need to meet rigorous confidentiality standards with a code used to identify participants and identifying information stored in an encrypted format (for follow-up purposes).

Data analysis will be completed by the main author. Data analysis will be completed including the performance of paired t-tests for the first phase and one-way ANOVA analysis for the second phase of the program evaluation. Data will be collected and entered into an Excel spreadsheet and the main author will complete statistical analysis. Data will be securely managed to protect participants’ information with additional cloud storage back up.
Chapter 5: Funding Plan

*Becoming Responsible: Transitioning to Adulthood* is a web-based resource for parents raising children with disabilities with primary goal of assisting parents in transferring responsibility for daily life task to youth with disabilities. The program is a stand-alone resource, which allows parents to login and access information including worksheets and information on how to progress their child through the four phases of the program to meet goals related to daily occupational performance problems.

In order to implement a successful program, thought must be given to the costs associated with its implementation as well as the funding sources to offset those costs. The cost-effective nature stills applies to this program; however, costs associated with web design, web domain, and dissemination efforts and maintenance must be considered. This chapter includes various avenues for funding.

First costs to be discussed are those associated with the design of the website as the implementation of the program is reliant on the creation of the website. Research has been completed regarding the costs to hire a private web designer, but the main author feels equip to build a website to accommodate the needs of the parents that will interact with the program. Simplicity and user-friendliness is most important in an effort to maintain parents interaction with the program. Research into the company, Wordpress, demonstrates it is a valid option for website development. Wordpress offers free software with templates to launch privately designed website (https://wordpress.com). Wordpress charges $25/year for using a private domain name. According to rates on GoDaddy.com, a private domain name (www.becomingresponsible.com) would cost $13.79/year.
Costs and permission for the use of several materials incorporated in this program must be considered. This author will seek initial permission for the use of Pediatric Evaluation of Disability Index (PEDI) - Responsibility Scale, in its modified form, from the authors for the first phase of the study. Permission from the authors will be revisited upon initiating the 2\textsuperscript{nd} phase of the study. This same process of obtaining initial permission and revisiting permissive rights with authors for 2\textsuperscript{nd} phase of the study would be addressed for the use of both the Self-Determined Learning Model of Instruction (SDLMI) and the Cognitive Orientation to Daily Occupational Performance (CO-OP) materials. Considering the small sample size of the initial pilot study (n = 10), it is assumed that the authors would not request payment for permission due to the small nature as well as extensive crediting to these authors within the program.

In both phases of the study, there are costs associated with mailing out the modified PEDI Responsibility Scale at pre-intervention and post-intervention follow-up. For pilot study, 10 envelopes would be mailed out with \textasciitilde12 pages (based on weight of one sheet of paper being .16 ounce) within the envelopes, including return address printed envelope with pre-paid postage. Mailing these out to study participants would cost $1.20/envelope with the total cost of $12.00 for the pilot study (www.usps.com). For the second phase of the study, with sample size of 30, totaling costs of $36 (www.usps.com). Returned envelopes would include pre-paid postage, which would total $19.60 based on 49-cent stamp rate (www.usps.com). Mailing costs for distributing the modified version of the PEDI Responsibility Scale totals $67.60.

There are in-kind local resources that can be considered to offset time spent by the
main author on program maintenance and updates. Abigail Lewis, a former classmate at Boston University that studied graphic design, is willing to assist with web design, marketing opportunities including updating social media platforms at no cost. Marissa Kelley, a lifetime friend, received her Bachelor of Science in Integrated Marketing Communication at Emerson College and would be able to provide additional assistance as needed at no cost with web design and marketing efforts as well as upkeep and updating of social media platforms.

A vital part of creating a successful program is ensuring it reaches its intended audience for its use. Dissemination efforts, detailed in Chapter 6, constitute the majority of costs associated with the implementation of this program. Dissemination efforts are geared to printing costs for posters presentations and brochures, and travel costs for presentation at various conferences. Total costs of dissemination efforts total $4,584.14. Considering the relatively lost costs for program implementation, this program remains highly cost effective. The total costs needing funding for the implementation of this program for the first two years, including use of private web domain name, mailing costs and dissemination is $4,744.02. Please see Table 5.1 for visual outline of costs for first two years of implementation.
Table 5.1: Budget for 1st Two Years of Implementation

<table>
<thead>
<tr>
<th>Budgeted Item</th>
<th>1st Year</th>
<th>2nd Year</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web Domain</td>
<td>$13.79</td>
<td>$13.79</td>
<td>GoDaddy.com cost for domain name.</td>
</tr>
<tr>
<td></td>
<td>$25.00</td>
<td>$25.00</td>
<td>Wordpress charges this amount for private domain name.</td>
</tr>
<tr>
<td>Total</td>
<td>$38.79</td>
<td>$38.79</td>
<td></td>
</tr>
<tr>
<td>Web Design</td>
<td>$0.00</td>
<td>$0.00</td>
<td>Friends: Abigail Lewis and Marissa Kelley have offered to assist with web design as previously mentioned.</td>
</tr>
<tr>
<td>Dissemination</td>
<td>Travel</td>
<td>Travel</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$750</td>
<td>$775</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Printing</td>
<td>Printing</td>
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<tr>
<td></td>
<td>$827.07</td>
<td>$987.07</td>
<td></td>
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<tr>
<td></td>
<td>Conference Registrations</td>
<td>Conference Registrations</td>
<td></td>
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<tr>
<td></td>
<td>$365</td>
<td>$880</td>
<td></td>
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<tr>
<td>Dissemination Total</td>
<td>$1,942.07</td>
<td>$2,642.07</td>
<td>Dissemination activities described in detail in Chapter 6.</td>
</tr>
<tr>
<td>Mailings</td>
<td>$12.00</td>
<td>$36.00</td>
<td>Mailing out modified PEDI Responsibility scale.</td>
</tr>
<tr>
<td></td>
<td>$4.90</td>
<td>$14.70</td>
<td>Cost for stamps for pre-paid postage on return envelopes. (post-intervention for pilot study; 6-month and 12-month follow-up for second phase of study)</td>
</tr>
<tr>
<td>Total:</td>
<td>$16.90</td>
<td>$65.40</td>
<td></td>
</tr>
<tr>
<td>Total:</td>
<td>$1,997.76</td>
<td>$2,746.26</td>
<td></td>
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</table>
Funding sources to offset these costs include angel capital from family and friends and the use of crowd source fundraising. Crowd source fundraising allows a person to create a campaign to raise money for a specific cause. For crowd source fundraising, GoFundMe.com will be utilized in hopes of raising ~$1,000. Donators will be provided with all information regarding the program, dissemination efforts and overall goals. These two avenues for funding may not be sufficient enough to cover the total costs, so federal grants have been researched to determine applicability of this program in meeting the goals of different organizations offering grants. The grants that have been considered are detailed in Table 5.2.

<table>
<thead>
<tr>
<th>Table 5.2: Grants Options</th>
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<tbody>
<tr>
<td><strong>Grant Title:</strong> NIH Small Grant Program: Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD): R03</td>
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<td><strong>HRSA-16-032 R40 Maternal and Child Health Research</strong></td>
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<td><strong>RGK Foundation</strong></td>
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</table>
| Community Parent Resource Center: 84.328C Special Education Parent Information Centers | • Research on programs relating to ensure, “parents of children with disabilities receive training and information to help improve results for their children” (Department of Health and Human Services, 2015)
• Supports programs to meet the needs of, “parents who experience significant isolation from available sources of information” (2015). The web-based nature and widely accessible nature would be fitting for grant.
• Goals of this grant are specified as “(a) meet developmental and functional goals and the challenging academic achievement standards that have been established for all children; and (b) be prepared to lead productive, independent adult lives to the maximum extent possible” (2015).
• Grant ceiling: $100,000. ([http://www.grants.gov/web/grants/view-opportunity.html?oppId=146653](http://www.grants.gov/web/grants/view-opportunity.html?oppId=146653)) |
| Special Education Research Programs: Families of Children with Disabilities 84.324A | • Supports research exploring and developing effective strategies for family support of children with disabilities to improve transition outcomes.
• Values the importance of parent involvement in education and the development of family-school partnerships.
• Becoming Responsible has the potential to further foster the development of the family-school partnership and improve transition outcomes.
• Maximum award for development project: $1,500,000. Grant reward is based on scope of project. ([http://ies.ed.gov/funding/ncser_rfas/ncser_families.asp](http://ies.ed.gov/funding/ncser_rfas/ncser_families.asp)) |
| Disability and Rehabilitation Research Projects (DRRPs): Community Living and Participation of Individuals with Disabilities 84.133A-4 | • Broadly supports research devoted to improving, “the effectiveness of services authorized under the Rehabilitation Act of 1973” (Department of Health and Human Services, 2015)
• Supports programs and interventions that seek to assist with improving independent living and employment outcomes for individuals with disabilities.
• Specific consideration is given to supporting health and function for transition-aged youth with disabilities (2015).
• Assumption of responsibility for daily life tasks may lead to improved independent living and employment outcomes.
• Grant awards up to $500,000. ([http://www.grants.gov/web/grants/view-opportunity.html?oppId=274651](http://www.grants.gov/web/grants/view-opportunity.html?oppId=274651)) |
| Special Education Research Programs: Autism Spectrum Disorders 84.324A | • Supports research on the development of programs to improve outcomes for students with Autism Spectrum Disorders (ASD) including those interventions that target parents, via home-based programs, with the goal of supporting education or transition outcomes (Institute of Education Sciences, 2015).
• *Becoming Responsible* target parents in the home setting to transfer responsibility for daily life tasks via the use of various, evidence-based strategies to improve transition outcomes to adulthood.
• Previously funded projects include: development of an intervention called Students with Autism Accessing General Education (SAAGE) Model (2015) and a comprehensive school-based intervention including social skills group, parent training and use of computer instruction on recognition of emotions by facial expression and vocal tones (2015).
• Grants awarded range from $500,000–$1,500,000 ([http://ies.ed.gov/funding/ncser_rfas/ncser_autism.asp](http://ies.ed.gov/funding/ncser_rfas/ncser_autism.asp)) |
| Deborah Munroe Noonan Memorial Research Fund | • Supports pilot studies, in the Boston metropolitan area, tailored to addressing quality of life for children and adolescents with disabilities (Health Resources in Action, 2015).
• Improving successful transition to adulthood for this population, through the assumption of responsibility for daily life tasks, may increase quality of life.
• Previously funded projects include: computerized cognitive training in adolescents with autism spectrum disorders, and Safety and Self-advocacy training for successful transitions from school to adult life (SST) (2015).
• Grants awarded up to $80,000. ([http://www.hria.org/tmfservices/tmfgrants/noonan.html](http://www.hria.org/tmfservices/tmfgrants/noonan.html)) |
Chapter 6: Dissemination Plan

_Becoming Responsible: Transitioning to Adulthood_ is a web-based parental resource for facilitating the transfer of responsibility for daily life tasks from parent to child. The program is widely accessible and seeks to synthesize two well-known, multicomponent interventions, The Self-Determined Learning Model of Instruction (SDLMI) and the Cognitive Orientation to Daily Occupational Performance (CO-OP). The program provides guidelines for parents to follow in order to set goals, develop an action plan and assess success related to reaching goals. The program offers handouts that are easily accessible for parents to print out and use when working on goals in the home setting. The program seeks to equip parents with skills similar to those held by occupational therapist, including analyzing performance of daily tasks and assessing where adjustments can be made, whether being through environmental modifications, practice and/or task gradation. The program is flexible which allows for parents and children to interact with the content to whatever extent necessary to reach youth-centered goals.

Disseminating this program to both the primary and secondary audiences will allow for more parent-child dyads to benefit from its use. The long-term goal of dissemination would be the incorporation of this program in outpatient occupational therapy programs and school-based services to facilitate carryover between home and school. A second long-term goal would be for this program to be a link option of the Massachusetts Department for Developmental Services. The short-term goal is to have this program implemented by a group of parents with children attending The Cotting
School and Perkins School for the Blind. The main author has connections to The Cotting School from completing Level II Fieldwork at this location as well as providing an introductory presentation on this project as part of completing fieldwork. Staff expressed interest in learning more once the project was completed. The main author also has connections with Perkins School for the Blind having completed a Level 1 fieldwork in the Early Learning Center.

Dissemination activities will begin in the early stages of phase 1, which is the pilot phase. Through the efforts detailed below, participants will be recruited to participate in the pilot study. Dissemination efforts will continue into 2\textsuperscript{nd} year to reach a larger audience for phase 2, which will encompass a fixed-effects research design.

The dissemination plan outlined below provides information regarding the target audiences, key messages, influential spokespersons and dissemination activities tailored to the specific audience. And finally, a detailed report of costs associated with these dissemination efforts is described for consideration in funding efforts noted in the previous chapter.

**Primary Target Audience**

The primary target audience of dissemination efforts would be special education providers and occupational therapists in school and outpatient settings working with youth with disabilities. Dissemination efforts for this audience would include presentations at Massachusetts Occupational Therapy Association (MAOT), American Occupational Therapy Association (AOTA), at two private, special education schools including The Cotting School and Perkins School for the Blind and a sensory integration
A clinic offering occupational therapy and speech and language pathology services, The Koomar Center OT Associates.

Key Messages for Primary Audience:

1. *Becoming Responsible* will assist in increasing independence with daily life tasks in the home setting for youth with disabilities and has the potential to help generalize these skills to the school setting.

2. *Becoming Responsible* can assist with achieving Individualized Education Plan (IEP) goals at school.

3. Continuing to educate and coach parents through the use of the *Becoming Responsible* program may influence positive outcomes.

Influential Spokesperson for Primary Audience:

1. Wendy Coster, OTR/L, PhD given her extensive experience and academic influence on the provision of occupational therapy services for children with disabilities.

2. Gael Orsmond, PhD given her research focus on increasing positive transition to adulthood for adolescents with autism.

3. Ellen Cohn, ScD, OTR/L given her experience with working with parents and children with disabilities to understand the phenomenon of social participation for this population in various settings.

Secondary Target Audience

The secondary target audience of dissemination efforts would be parents of youth with disabilities attending outpatient and school settings of the primary target audience.
Presentations developed for the parent population could be delivered at Perkins School for the Blind, The Koomar Center and The Cotting School. Providing brochures to these three locations would be an additional way to reach out to this audience. Furthermore, both schools have publications including Perspectives [magazine], Perkins Vision [blog], www.Wonderbaby.org and Cotting Connections, which could be utilized to publish content and send out information for parents to access at home if unable to attend a special parent-based presentation of the material. And finally, creating accounts for the program and utilizing Facebook, Twitter and LinkedIn as other social media strategies would be an effective strategy for reaching this target audience as many parents take to these websites to seek out support and answers for parenting challenges.

Key Messages for Secondary Audience:

1. *Becoming Responsible* is a flexible and feasible option for use in everyday context.

2. Parents report being satisfied with positive outcomes after using the Becoming Responsible program.

3. Children responded well to participating in the program and majority met at least 2 of 3 set goals from pilot study.

Influential Spokesperson For Secondary Audience:

1. Parents with successful use with the program during the pilot study

Tertiary Target Audience

The tertiary target audience of dissemination efforts would be other stakeholders including those in the larger disability community, including Easter Seals of
Massachusetts and the Massachusetts Department of Developmental Services.

Presentations of the program and lived experience success stories would provide the support for the real life applicability of the program’s success. Providing brochures to these organizations may assist with raising awareness of the program. The program is cost-effective as it has minimal costs to implement as the program serves as a stand-alone, web-based resource for parents. The cost-effective nature of this program, may appeal to these larger organizations.

Key Messages for Tertiary Audience:

1. Participants increased self-determination after engaging in this program.
2. Participants increased Modified PEDI Responsibility Scale scores after engaging in this program.
3. Participants reported 95% satisfaction with the program during the second phase of the study.
4. Participants with successful participation with this program were more likely to be employed after 2-year follow-up for those at transition age.

Influential Spokespersons for Tertiary Audience:

1. Legislator with experience advocating for Occupational Therapy
2. Occupational Therapist from outpatient setting
3. Parent with successful use with the program
### Table 6.1 Budget for Dissemination Plan:

<table>
<thead>
<tr>
<th>Audience</th>
<th>1st Year</th>
<th>2nd Year</th>
</tr>
</thead>
</table>
| **Primary** | Travel: $600  
Print (250 brochures from FedEx Kinkos): $299.99  
Print (Scientific poster from Omnipress): $87.10  
Conference Registrations:  
• American Occupational Therapy Association (AOTA): $300  
• Massachusetts Association of Occupational Therapy (MAOT): $65 | Travel: $600  
Print (250 brochures from FedEx Kinkos): $299.99  
Print (Scientific poster from Omnipress): $87.10  
Conference Registrations:  
• American Occupational Therapy Association (AOTA): $300  
• Massachusetts Association of Occupational Therapy (MAOT): $65  
• Council on Exceptional Children Special Education Conference and Expo: $515 |
| **Secondary** | Travel: $50  
Print (100 brochures): $139.99  
Presentation: PowerPoint/Time (no cost)  
Blogging/Updating Social Media: Time (no cost) | Travel: $75  
Print (250 brochures): $299.99  
Presentation: PowerPoint/Time (no cost)  
Blogging/Updating Social media: Time (no cost) |
| **Tertiary** | Travel: $100  
Print (250 brochures): $299.99  
Presentation: PowerPoint/Time (no cost) | Travel: $100  
Print (250 brochures): $299.99  
Presenters: Parents from pilot study (nominal fee)  
Presentation: PowerPoint/Time (no cost) |

First Two Years Total Costs: $4,584.14

Subsequent years would likely follow similar funding needs depending on success of program as well as likely increases in pricing.
Chapter 7: Conclusion

*Becoming Responsible: Transitioning to Adulthood* seeks to lessen the discrepancy between youth with disabilities and those without in respect to successful transition to adulthood (Kuriyan et al., 2012; Wells, Sandefur & Hogan, 2003; Janus, 2009; Dunn, 1996). The web-based nature of this program makes it highly accessible for use by parents looking for guidance on how best to transfer responsibility for daily life tasks to their children and teens with disabilities. Evidence shows that parents raising children with disabilities experience more stress, which may negatively impact healthy parent-child relationships and overall quality of life (Respler-Herman, Mowder, Yasik & Shamah, 2012; Totsika, Hastings, Vagenas & Emerson, 2014; Neece, Green & Baker, 2012). Therefore, providing additional support to manage the challenges of parenting is important.

The bioecological model of human development authored by Urie Bronfenbrenner was used as the theoretical foundation for understanding the problem. Specifically, the proximal processes described in the model emphasize the vital role that parents play in children’s development (Bronfenbrenner & Morris, 2006). Similarly, the bioecological model is in line with the values of the occupational therapy profession because it emphasizes the interplay between the person, environment and occupation (Law, 1996). The program seeks to utilize all three of these areas to maximize function and participation of both parents and youth through modifications of tasks and environments for increased independence.

A thorough literature review was performed in order to identify existing evidence-
based programs that have attempted to address this problem. Two interventions were identified by the author as the most appropriate for the development of the program: The Self-Determined Learning Model of Instruction (SDLMI) and the Cognitive Orientation to Daily Occupational Performance (CO-OP) (Wehmeyer, 2007; Wehmeyer, Shogren, Palmer, Williams-Diehm, Little & Boulton, 2012; Wehmeyer, Palmer, Shogren, Williams-Diehm & Soukup, 2013; Polatajko & Mandich, 2012). In this program, these two interventions are synthesized into one comprehensive program that facilitates the transfer of responsibility from parent to child using four phases of problem-solving questions (GOAL-PLAN-DO-CHECK) (Polatajko & Mandich, 2012).

The materials developed for this program include printable worksheets and handouts for parents to use in order to facilitate the transfer of responsibility for daily life tasks from parent to child. The website includes an introduction to the program as well as advise as to how to interact and utilize the worksheets. Significant time was spent in the development of the program’s worksheets for parent accessibility. The worksheets follow the four phases of GOAL-PLAN-DO-CHECK including guidance on how to set goals, how to observe where the child is experiencing performance problems, how to utilize guided discovery and how to utilize teaching strategies to promote learning.

* Becoming Responsible: Transitioning to Adulthood will be evaluated through two phases of pre-post test studies. The first phase will be a small pre-post test study (n = 10) with follow-up telephone interviews at 6-months. The second phase will be a larger scale pre-post test (n = 30) with follow-up at 6-months and 12-months. The results of the first phase of the program evaluation will assist with making adjustments to the program to
best meet the needs of the parents interacting with the materials. Program improvements will aid in reaching both short term and long-term goals identified in the dissemination plan.

**Summary**

Transferring responsibility from parent to child is an important phenomenon in development. Parents raising children with disabilities may experience additional challenges in doing so, which may impact social-emotional wellbeing. Parents’ use of the materials developed for this program may improve social-emotional wellbeing, improve transition outcomes of youth with disabilities and improve overall quality of life. The web-based and highly flexible nature of the program allows parents to implement the program based on what they think will work best for their child.
Appendix A: Evidence to Support the Proposed Explanatory Model

Search Question #1: What is the evidence that young people with disabilities are less successful transitioning to independent living?

<table>
<thead>
<tr>
<th><strong>Author &amp; year of publication</strong></th>
<th><strong>Type of report/Study Design</strong></th>
<th><strong>Participant characteristics &amp; selection</strong></th>
<th><strong>Site/context of study</strong></th>
<th><strong>Variables &amp; measures</strong></th>
<th><strong>Procedures</strong></th>
<th><strong>Key findings</strong></th>
<th><strong>Application</strong></th>
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<tbody>
<tr>
<td>Kuriyan, A. (2012).</td>
<td>Prospective longitudinal study comparing educational and vocational outcomes for youth with ADHD and a comparison group with no ADHD.</td>
<td>Sample = 493 participants from the Pittsburgh ADHD Longitudinal Study (PALS). First follow-up interview, ADHD group ranged in age from 11-28 years old, with 99% btw 11-25 yrs. Demographics: The ADHD &amp; comparison group: comparison that was &gt;.05 (Voc/tech vs. Jr/Community) all other comparisons were not statistically significant.</td>
<td>Pittsburgh, PA; participants were treated in the Summer Treatment Program (STP) at the Western Psychiatric Institute and Clinic (WPIC).</td>
<td>Educational Information, academic problems, disciplinary problems, IQ and achievement, vocational information</td>
<td>PALS Interviews were conducted-annual follow-up Children with ADHD underwent an assessment including parent and teacher Diagnostic &amp; Statistical Manual of Mental Disorders symptom ratings &amp; semi-structured interview.</td>
<td>Overall group effect was found for ADHD. ADHD group was less likely (then comparison group) to pursue education post-high school. ADHD group was less likely to be in four-year college relative to no school, to vocational/technical school, or to junior/community college relative to not in school.</td>
<td>This article answers my research question by providing evidence that this particular group (Those with ADHD) are less successful in transitioning to independent living in terms of managing post-high school education and maintaining employment.</td>
</tr>
<tr>
<td>Wells, T., Sandefur, G. &amp; Hogan, D. (2003).</td>
<td>Longitudinal studies: National Longitudinal</td>
<td>NLTS: Original sample: &gt;8,000 youth with disabilities, aged</td>
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<td>Youth with disabilities are more likely to be very dependent.</td>
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<tr>
<td>Year</td>
<td>Study Description</td>
<td>Sample Notes</td>
<td>Marriage, Parenthood Notes</td>
<td>Transition into Adulthood Notes</td>
<td>Notes</td>
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<tr>
<td>1987-1991</td>
<td>Transition Study of Special Education Students (NLTS) 1987-1991 &amp; National Educational Longitudinal Study (NELS) of 1988</td>
<td>13-21 (disability status and type were determined through school records) NELS: cohort of 8th graders with disabilities (disability status and type was determined through student self-report), those with severe disabilities excluded</td>
<td>Same as above</td>
<td>transition into adulthood was largest (44% and 42% respectively) Women (no disability) on NELS: latent class 3 (single, enrolled in postsecondary school, if working only part time, living at home and living independently) = 70% Men (no disability) on NELS: latent class 3 = ~70% than youth without disabilities Youth with disabilities are not as successful in transitioning to adulthood as non-disabled peers</td>
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<tr>
<td>2009</td>
<td>Latent class and multinomial analysis Studied the same adults at age 26 as Wells, Sandefur &amp; Hogan did at age 20</td>
<td>Same population as above</td>
<td>Same as above</td>
<td>Categorized into different groups using data on multiple facets of transition to adulthood (32 possible groups) Latent class analysis and multinomial logistic regression analysis &quot;Laggards&quot; latent class (~3% of sample) – no adult transitions were completed by majority in this latent class Visual, Hearing, speech, &quot;Other&quot; impairment found to decrease odds of belonging to the other groups compared to &quot;laggards&quot; group *Reference of Arnett (1998) Demonstrates significant gap btw disabled and nondisabled outcomes (p. 115) Those found in “laggards” group – more likely experience low family incomes, employment in low-level service/office jobs, dissatisfied with romantic relationships and high rates of illegal behavior</td>
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<td>Haveman, M. et al. (1997)</td>
<td>Qualitative, subjective report</td>
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<td>Large (n=2,573), unselected sample of parents raising a child with special needs (&quot;MR&quot;) in the Netherlands (selected from all organizations that would have contact with the families)</td>
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*Comparison to all Dutch families was used only for demographics |
| Netherlands Families in contact with organizations raising child with special needs |
Majority married (86%)
Majority of families had only one child with special needs (86%) |
| Questionnaire with 146 questions on parent characteristic, child characteristic (used 8-item Maladaptive Behavior Scale for one measure within this), service needs and use, objective time demands and subjective caregiving (Time Demand-Index of Heller & Factor) (9-item Caregiving Burden-Scale) |
| Participating families received questionnaire in the mail, primary caregiver completed and returned it |
| Age group differences: age phases differed significantly in all variables with exception of child's gender
- Adaptive skills are lowest for youngest age group and more severe MR
- Families of older children use less formal services than families of younger children Service Needs: ages 10-19: top need: direct support to the child regarding developmental issues (67%), second key need is for information and advice about future residential living |
<p>| Parenting a child with and without a disability = time demands decrease; however, parenting an adult-child with a disability - hours of care are still considerable (which may equate to less successful transitioning to adulthood) Perceived burden did not decrease with adulthood - may demonstrate that an adolescent with disabilities did not transition as successfully into adulthood Limitations: not a comparison to families without a child with MR Performed in the Netherlands (may be a different experience in USA) |</p>
<table>
<thead>
<tr>
<th>Dunn, C. (1996)</th>
<th>Review of transition services</th>
<th>Focus on services for individuals with learning disabilities</th>
<th>Written in 1996 – not the most up to date information but the question does not require it to be</th>
<th>Review of programs – no variables/variables</th>
<th>No Procedures</th>
<th>In one study (Levin, Zigmond, &amp; Birch, 1985), found that 47% of students with a LD dropped out compared to 36% of nondisabled peers. Various studies, “indicate that compared to their nondisabled peers, individuals with mild disabilities experience unemployment/dissatisfaction, less participation in community, lower pay, dependency on parents, higher academic failure in postsecondary settings (p. 17) Hoffman et al, 1987 found that adults with LD have limited independent-functioning skills</th>
<th>Good comparisons between individuals with LD to nondisabled peers demonstrating less successful transition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timmons, J et al. (2004)</td>
<td>Qualitative study of parents of young adults with disabilities</td>
<td>Parents (n=30) varying ethnic and linguistic backgrounds, resided in urban, suburban and</td>
<td>Focus groups were conducted 5 times in 4 different locations</td>
<td>Focus groups and case studies</td>
<td>Data collection: focus group and case studies were coded and analyzed</td>
<td>Service delivery systems are inconsistent, complex and unresponsive</td>
<td>Can also return to this article as it relates to parental vs. child responsibility</td>
</tr>
</tbody>
</table>
who have identified needs for support from health care and adult service agencies after exiting high school

<p>| Friedman, D. et al. (2009) | Trajectory comparison study using individual growth curve modeling procedures to compare children/adol | N= 68 (at Time 1) ages 9-15 with spina bifida (recruited from hospitals, and statewide spina bifida association) and N=68 of nondisabled peers | Loyola University Chicago conducted the study Every 2 years, 3-hour long session held at participants’ | Demographics, Autonomy development (behavioral, emotional, Decision-Making Questionnaire), observed | Data collected at family’s home – completed questionnaires, and a series of videotaped family interaction tasks (unfamiliar board game and conflict) | “in general, children with spina bifida and their age-matched peers both show increases in independent behavior and emotional | Challenges in day-to-day life “preclude any meaningful planning on their part for their children’s future” → may demonstrate a focus on providing care and oversight (“managing everyday responsibilities and obligations” “general plans and preparation involved their children acquiring skills, expanding their social and vocational capacity, developing a support network, and exposing their children to varied vocational and life experiences” (p. 22) |</p>
<table>
<thead>
<tr>
<th>Frisch, D. et al. (2013)</th>
<th>Literature Review</th>
<th>Adolescents and adults with cerebral palsy</th>
<th>Reviews literature using the ICF model and lifespan perspective</th>
<th>Table 1 lists assessments that are used with this population</th>
<th>Does not detail the way the lit review was performed</th>
<th>One study – “even among those with the highest motor functioning ratings and no substantial</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Table 1 lists assessments that are used with this population</td>
<td>Does not detail the way the lit review was performed</td>
<td>One study – “even among those with the highest motor functioning ratings and no substantial</td>
<td>Many other studies within this review answer this question – may</td>
</tr>
<tr>
<td>escents with and without spina bifida – part of a larger longitudinal investigation</td>
<td>house</td>
<td>dependent behavior (5-point Likert scale ratings), Intrinsic Versus Extrinsic Orientation in the Classroom Revised (teacher report), Emotional Autonomy Scale, PPVT-R (intellectual functioning), Issues Checklist</td>
<td>task)</td>
<td>autonomy from their parents over time” but “in certain areas, however, children with spina bifida appear to lag behind their peers with regard to autonomy development” (p. 22-23)</td>
<td>“at age 15, children with spina bifida continued to demonstrate significantly more dependent behavior in observed family interactions” (p. 23)</td>
<td>peers. Great example of outcomes to consider – may return to this article for another question</td>
</tr>
</tbody>
</table>
cognitive impairment, the majority had lower levels of education, employment, independence, and involvement in romantic relationships compared to peers without CP (p. 90) look into some of the references Youth with CP experience difficulties with adult transition when compared to peers without CP.
**Search Question #2:** What theories and evidence are available regarding factors that contribute to more and less successful assumption of adult responsibilities by young people with disabilities?

- How do differences in parenting styles affect the transfer of responsibility from parent to child?
- Are parents of youth with disabilities more likely to restrain or inhibit their development of independence and autonomy?
- Do parent beliefs about disability play a role in how they prepare their child for adulthood?

<table>
<thead>
<tr>
<th>Author &amp; year of publication</th>
<th>Type of report/study design</th>
<th>Participant characteristics &amp; selection</th>
<th>Site/context of study</th>
<th>Variables &amp; measures</th>
<th>Procedures</th>
<th>Key findings</th>
<th>Application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respler-Herman et al. (2012)</td>
<td>Investigative study</td>
<td>Parents of preschool and elementary students (n = 87) 74.7% female 24.1% male 92% Caucasian 93.1% children no special needs 3.4% children special needs</td>
<td>East coast (2 private, small, suburban schools) Parenting in relation to parental stress and social support</td>
<td>Parent Behavior Importance Questionnaire-Revised (PBIQ-R): assess parent beliefs on parenting behaviors (seven domains) Parenting Stress Index-Short Form (PSI-SF) Multidimensional Scale of Perceived Social Support (MSPSS)</td>
<td>Instructions, and questionnaires given to parents to fill out (response rate 61.8%)</td>
<td>More parenting stress was related to less positive parenting beliefs re the importance of parenting behaviors Total social support did not moderate relation btw parenting stress and parenting beliefs re parent behavior importance</td>
<td>Parents that report stress endorse negative parenting behaviors as important Provides evidence for offering workshops for parents to help incorporate strategies to reduce parenting stress (197) Help facilitate development of parent education to help parents parent more successfully *Scan reference list</td>
</tr>
<tr>
<td>Jivanjee et al. (2009)</td>
<td>Qualitative Study</td>
<td>Family members (n=42) supporting children with mental health difficulties 4 Northwest states formed local advisory groups Recruited</td>
<td>4 Northwest states formed local advisory groups Recruited</td>
<td>Demographic information gathered from surveys (diagnostic</td>
<td>Focus group: questions were developed – sessions were</td>
<td></td>
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</tr>
</tbody>
</table>
| Kim & Mahoney (2004) | Group comparison study | Male = 2  
Female = 40  
85% European American  
26% of children learning disability  
43% of children ADD | participants for focus groups (20, 90-minute focus groups) | information, living situation and educational and employment status  
Qualitative questions delivered to focus groups | audiotaped, analyzed |  
Qualitative questions delivered to focus groups | Audiotaped, analyzed | 
Korea – urban areas  
Recruited from special education institute | Korean Vineland Social Maturity Scale  
Video observation – children’s engagement = Child Behavior Rating Scale  
Mother’s engagement = Maternal Behavior Rating Scale | 10-minute videotaped session of child playing with their mothers (w/ dev appropriate toys) | Mothers of children w/ dis: lower scores on responsiveness & affect, & higher scores on directiveness than did mothers with children w/o dis  
Children’s engagement significantly corr w/ maternal responsiveness, affect, and children’s disability  
Responsiveness and affect strong predictors of how engaged children were than dev status | Parental influence on child behavior  
Maternal directiveness occurred more with children with disabilities |
<table>
<thead>
<tr>
<th>Carter et al. (2009)</th>
<th>Investigative study</th>
<th>High school students w/ dis (n=135) assessed by SpEd teacher and/or parents Mean Age = 18.3 y/o (51.1% male) 85.3% cognitive disabilities 86.7% European Americans</th>
<th>29 different high schools (rural, suburban, urban) in Wisconsin</th>
<th>AIR Self-Determination Scale—AIR (capacities and opportunities to engage in self-determined behaviors) completed by teachers and parents Social Skills Rating System – Secondary Teachers Version- SSRS</th>
<th>Recruited participants for larger study Assessments distributed</th>
<th>Teachers rated abilities of youth to perform self-determination behaviors significantly higher than parents’ ratings No significant differences were found btw teachers’ and parents’ ratings of opportunities at school or at home</th>
<th>Parents may underestimate children’s capacity to perform self-determination behaviors – which may limit the opportunities parents provide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carter et al. (2013)</td>
<td>Investigative study</td>
<td>Parents or caregivers of children w/ ID or autism (n=627) Children (91.4% White)</td>
<td>The role parents play in fostering self-determination among their children with dis 34 randomly selected public school districts Wisconsin (same as above)</td>
<td>Study-developed questionnaire for parents to complete (self-determination – importance, extent of performance, barriers and recs for schools/other parents Seven component self-determination skills 3-point Likert AIR Self-</td>
<td>Mailed out surveys to recruited parents (Response rate = 37.7%) Descriptive stats, Pearson correlation, regression analysis</td>
<td>Parents rated it very important for children to learn the 7 component skills Parents generally reported children did not perform these skills well Low level relation between performance and importance Parents reporting child w/ severe/profound dis placed less</td>
<td>Parents value self-determination skills Parents low score of capacity across age may demonstrate comparison to age-expected skills May not have the strategies to foster self-determination skills Need for home-based interventions to enhance self-determination</td>
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<td>Study</td>
<td>1st study:</td>
<td>2nd study:</td>
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<td>Saaltink et al. (2012)</td>
<td>phenomenological research</td>
<td>same as above</td>
<td>families with child w/ ID (n = 10 from 4 families) Child age = 14-18 y/o</td>
<td>one child and one mother from previous study</td>
<td>themes</td>
<td>themes</td>
<td>Decision-making processes framed by family norms and values – protect people with ID (vulnerable) Decision when outcome only affects the decision maker (what to wear, what to eat, how to spend free time) were made with autonomy – persuaded decisions that remain w/in the family values, conventions and safety</td>
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<tr>
<td>Totsika et al. (2014)</td>
<td>Investigative study using existing cohort design controls</td>
<td>British birth cohort (MCS) Cohort 1 (MCS1) = 18,818 MCS2 = 15, 590 MCS3 = 15,246 (n=516 with ID) 66% male, 47% of children lived in households where all parents were unemployed</td>
<td>Exiting cohort study used for representative sample Britain (Centre for Longitudinal Studies in the Institute of Education in the UK)</td>
<td>Cognitive: British Ability Scale Children’s behavior problems: Strengths and Difficulties Questionnaire (SDQ) Parenting: discipline use, home environment and child/parent relationship (5-point Likert scale) Quality of child/parents</td>
<td>Identified 5 y/o and tracked back to ensure participation in first two waves Series of path models in AMOS 18 (SEM)</td>
<td>Parents of children w/ ID perceived their relationship wi/ child = more conflict and less closeness than parents with child w/o ID Each parenting variable was individually associated with children’s behavior problems Closeness and conflict significant associations at both ages</td>
<td>p. 431: more negative relationships might be related to fewer fxl skills (impede typical patterns of interactions btw mothers and children) Parent-child relationship emerged as significant corr of beh problems in young children with ID Reducing conflict may be important to address in parenting programs</td>
</tr>
</tbody>
</table>
Greenberg et al. (2012) conducted a multisite study, using data from a larger longitudinal study – one wave (cross-sectional data). The sample included families with children (n = 167), adolescents (n = 85), and adults (n = 34). The sample was majority male (83%, 84%, 94%) and predominantly White (94% for children with Fragile X, 94% for mothers of adolescents, and 75% for mothers of adults). Most of the mothers were married (84%, 82%, 94%) and had some college education (88% for mothers of children with Fragile X, 83% for mothers of adolescents, and 88% for mothers of adults). The study recruited participants through service agencies, clinics, and foundations in the US.

The study used the Five Minute Speech Sample (family environment) to assess overinvolvement and overprotectiveness. Measures included criticism, emotional overinvolvement, positive remarks, warmth, and child behavior problems (Child/Adult Behavior Checklist). Mothers were interviewed at home or by telephone and completed self-administered measures (coded for content and tone).

Mothers of children with ID engaged in more negative and less positive parenting than mothers of children without ID. (important in long-term) Mothers of children with ID engage in more negative and less positive parenting than mothers of children without ID. Mothers of adolescents – higher levels of overinvolvement (compared to mothers of children). Criticism was significantly associated with total problems for adolescents. Mothers may demonstrate overprotectiveness with adolescents with Fragile X.
| Neece et al. (2012) | Investigative, longitudinal | Families (n = 237) recruited an existing longitudinal study (Collaborative Family Study) Families with child w/ DD recruited through service agencies Children ages ranged: 3-9 yrs Males = 57.8% Mothers, 60.1% White | PA (n = 41), CA (n = 196) thru area universities | Family Impact Questionnaire Child Behavior Checklist Stanford-Binet Intelligence Scale | Ages: 3, 5 and 9, family came into center for assessment. Ages 3, 4, 6, 7, 8 investigators went for home visit. Parenting stress questionnaire mailed home and completed before visit. | HLM analyses | Covariation of parenting stress and child behavior problems across time Decrease in behavior problems across time Parents of child with DD had significant higher initial levels of parenting stress compared to non-DD parents Parenting stress and child behavior problems are both antecedents & consequences of one another Transactional relationship appears to be similar for children w/ & w/o disabilities | Provides additional support for parent education program – may reduce parenting stress and child problem behaviors |
## Appendix B: Evidence of Current Approaches and Methods

**Search Question #1**: Is there evidence that self-determination interventions are effective in improving transition to adulthood for youth with disabilities?

<table>
<thead>
<tr>
<th>Author and year of pub.</th>
<th>Type of report/study design</th>
<th>Participant characteristics and selection</th>
<th>Site/context of study</th>
<th>Variables and Measures</th>
<th>Procedures</th>
<th>Key Findings</th>
<th>Application</th>
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</thead>
<tbody>
<tr>
<td>Shogren et al. (2015)</td>
<td>Follow-up analysis from previous RCT looking at efficacy of self-determination intervention on secondary school outcomes</td>
<td>Students with disabilities (n=779) recruited from 6 states Age: M= 17.1, SD = 1.5 61.1% male 56.7% white 37.4% LD 29.9% ID 6% Autism</td>
<td>Group-randomized, control group</td>
<td>Arc’s SDS, 72-item self-report measure Outcomes used in National Consumer Survey and National Longitudinal Transition Study (employment, community access, financial independence, independent living)</td>
<td>Surveys sent to contact addresses SEM Parceling Confirmatory Factor Analysis (CFA)</td>
<td>SDS at Time 3 significantly predicted Community Access at time 4 SDS at Time 3 significantly predicted employment at time 4, but not at Time 5 – however employment at time 4 predicted employment at time 5 showing indirect effect of SD</td>
<td>Self-determination interventions may impact outcomes in youth with disabilities in transitioning to adulthood</td>
</tr>
<tr>
<td>Wehmeyer &amp; Abery (2013)</td>
<td>Literature review</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Review of databases</td>
<td>Youth/Adults w/ IDD are less self-determined than nondisabled peers Youth/Adults w/ IDD can become more self-determined if given adequate supports</td>
<td>Providing self-determination interventions are valued and effective in improving adult outcomes</td>
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<tr>
<td>Study Authors</td>
<td>Study Design</td>
<td>Sample Description</td>
<td>Data Collection Methods</td>
<td>Findings</td>
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<td>Palmer, Wehmeyer, Shogren, Williams-Diehm &amp; Soukup (2012)</td>
<td>Longitudinal study</td>
<td>N = 109 high school student in 3 states receiving special education (ID)</td>
<td>Arc’s Self-Determination Scale</td>
<td>Significant overall effect of time with students showing a significant increase in their self-determination scores from baseline to postintervention</td>
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<td>Texas, Kansas, Missouri, 23 school districts</td>
<td>Beyond High School intervention over 2 year period, also used SDLMI Training provided to educators</td>
<td>BHS used in conjunction with SDLMI is effective in increasing self-determination scores from baseline to postintervention</td>
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<td>Shogren, Palmer, Wehmeyer, Williams-Diehm &amp; Little (2012)</td>
<td>Randomized trial study</td>
<td>n = 312 with ID or LD, high school students</td>
<td>Goal Attainment Scaling (GAS) Access CISSAR (data collection system)</td>
<td>significant changes in the goal attainment and access to the general education curriculum of students with intellectual and Self-determination intervention such as the SDLMI is effective in education</td>
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<tr>
<td>Study</td>
<td>Type of Study</td>
<td>Setting</td>
<td>Sample Description</td>
<td>Measures</td>
<td>Results</td>
<td>Conclusion</td>
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<tr>
<td>Wehmeyer, Shogren, Palmer, Williams-Diehm, Little &amp; Boulton (2012)</td>
<td>Group randomized, modified equivalent control group time series</td>
<td>N = 312 high school students – Texas, Missouri, Kansas</td>
<td>44% female ages: 13.5-21.3 years SDLMI</td>
<td>Arc’s Self-Determination Scale AIR Self-Determination Scale Performed power analysis of previous data</td>
<td>Intervention group showed significant improvements on both the AIR and SDS Those with learning disabilities showed greater increase in SD compared to intellectual disabilities</td>
<td>SDLMI showing effectiveness in education setting with wide age range Those with LD may benefit more than those with ID</td>
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<td>Mazzoti et al. (2013)</td>
<td>Systemic replication of Mazzoti (2012) Multiple probe across participants design</td>
<td>Public, urban elementary school in southwestern USA (student population of 953; 64% African American, 22% Caucasian, 10% Hispanic, 2% Asian, 1% American Indian, 1% unspecified)</td>
<td>N = 4 Aged 10 and 11 Student at risk for emotional disturbance (based on screening: Student Risk Screening Scale) exhibiting disruptive SRSS, 4-point Likert scale, teacher rating of behaviors (7 items) Disruptive behavior based on observation during 12 minutes of classroom time Knowledge of self-determination based on 27-point</td>
<td>Computer-assisted instruction SDLMI adapted into Multimedia goal-setting intervention (MSGI): set a goal, make a plan, adjust your goal Intervention sessions conducted</td>
<td>Determined interrater reliability (mean = 98.1%m ranging 88.8-100%) Determined social validity: 4-point Likert scale (teachers and students each provided one at end) – good feedback</td>
<td>Functional relationship between MGSI and students’ increased knowledge of SDLMI and decreased disruptive behavior 3 participants maintained knowledge of SDLMI and low...</td>
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<td>Palmer &amp; Wehmeyer (2002)</td>
<td>Parent guide to self-determination</td>
<td>Behavior probe: ability to orally define 3 basic parts (4 questions/parts) questions and 12 supporting questions</td>
<td>Individually in small tutoring rooms. Intervention session daily – students trained to navigate course (15 minute sessions) – end of session, probes collected of knowledge then data collected on disruptive behavior. Data collected during baseline (lowest behavior and most stable baseline entered first), once a week during intervention, once a week during maintenance</td>
<td>Levels of disruptive behavior for 3 consecutive weeks after removing MSGI, 1 student maintained for 1 week. Evidence of importance of goal setting and self-management for this population, and may generalize to other disability populations. Shows self-determination is teachable</td>
<td>Good ideas to include in my structure of</td>
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</table>
| Wehmeyer, Palmer, Shogren, Williams-Diehm & Soukup (2013) | Randomized trial placebo control group study | N = 317 receiving special education services under ID or LD | ID = 28%  
LD = 72%  
Arkansas, Kansas, Missouri, Nebraska, Oklahoma, Texas  
Ages 14-20 years old  
54% Caucasian  
25% Hispanic  
African American  
16% | Arc’s Self-Determination Scale  
AIR Self-Determination Scale  
Questions taken from Whose Future Is It Anyways? | Trained providers in intervention  
Treatment group – teachers randomly assigned to intervention condition selected from menu of interventions  
Placebo control group intervention to minimize attrition from control group (intervention not expected to impact scores) | Multigroup model – significant overall increase in AIR-S score over time  
- intervention group showed significantly more positive increases on AIR-S (no difference between age, gender or disability)  
SDS showed significant increase in scores over time | Self-determination interventions results in significant changes in student self-determination |
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<tr>
<td>Study analyzed subset of data from larger study of Youth En Route (YER)</td>
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<td>Longitudinal study</td>
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<td>N= 34 individuals</td>
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<td>17 males, 17 females</td>
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<td>17-29 years</td>
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<td>27% spina bifida</td>
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<td>24% CP</td>
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<td>49% various conditions</td>
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<tr>
<td>Ontario, Canada</td>
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<tr>
<td>Pediatric rehab center and community agency for adults with disabilities</td>
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<tr>
<td>Arc’s Self-Determination Scale</td>
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<td>Life Satisfaction Index-Adolescents</td>
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<td>YER program provided to youth and adults with chronic health conditions.</td>
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<td>Study conducted from Dec 2000-March 2004, average duration of program of 10 months. 12-month follow-up from end of program.</td>
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<td>Study looked at relationship between SD and subdomains of perceived QOL over time – SD was a significant predictor of perceived QOL w/ respect to personal development and personal fulfillment over course of 1 year.</td>
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<td>Programs supporting SD at time of transition may impact QOL in this population.</td>
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</table>
| Powers et al. (2012) | Longitudinal, randomized study  
(two independent groups x three repeated design) | N = 69  
(n = 33 intervention, n = 36 comparison)  
Ages 16.5-17.5  
Females =41%  
Receiving special education  
Under guardianship of Oregon DHS  
Assigned randomly to either TAKE CHARGE intervention or foster care independent living program (ILP) | Oregon Adolescents in state foster care system | Arc SDS Quality of Life Questionnaire  
Transition Planning Assessment  
The Outcome Survey (self-report measures perceptions on readiness for independent living) – employment, education, living status | Randomly assigned to either group  
Enrolled in 3 study waves  
Assessed at baseline, post-intervention and one year follow-up  
TAKE CHARGE – participants for 12 months presented in self-help guide (weekly, coaching sessions and quarterly workshops with adult mentors)  
Mixed models Variance-covariance structure | Intervention group scored significantly higher than comparison group at post-intervention and follow-up  
Intervention group reported significantly higher quality of life than comparison  
Self-determination is a partial mediator of quality of life | Study provides proof to consider benefits of coaching in youth-directed identification and pursuit of goals and mentoring experiences offered thru self-determination enhancement models  
Could be beneficial in supporting youth in foster care and special education to promote transition success  
Intervention grouped reported higher engagement in

- TAKE CHARGE
- Oregon Adolescents in state foster care system
- Arc SDS Quality of Life Questionnaire
- Transition Planning Assessment
- The Outcome Survey (self-report measures perceptions on readiness for independent living) – employment, education, living status

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<tr>
<th>Time 2</th>
<th>Face-to-face interviews</th>
<th>(time 2) face-to-face interviews</th>
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<tr>
<td>Algozzine et al. (2001)</td>
<td>Meta-Analysis of Research conducted in re: self-determination</td>
<td>N = 51 studies reviewed and 22 studies included in the study meeting criteria</td>
<td>Databases searched: ERIC, EBSCO-Host, PsychInfo, Dissertation Abstracts International, Council for Exceptional Children</td>
<td>Calculated effect sizes</td>
<td>See other columns</td>
<td>Summary chart including all articles and their outcomes</td>
<td>key independent living activities post and follow-up (compared to control) - generalization</td>
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</table>
|------------------------|---------------------------------------------------------------|-----------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------|-----------------------------------------------------------------|-----------------------------------------------------------------|-----------------------------------------------------------------
|                        |                                                               | Between 1972 and 2000 | List search terms and journals used | Group studies = d-index effect size (n= 9) | Effect sizes and study coding (interrater reliability) | Average effect size = 1.38 (moderate gains in self-determination), median effect size .60 | Most common interventions were self-advocacy and choice making |
|                        |                                                               | Subjects had to be individuals w/ disabilities, ages 3 to adulthood | Data based intervention | Single-subject studies (n=13) = nonoverlapping data (PND) between tx and baseline phases to determine intervention effects | N = 29 used qualitative data and not usable | Single subject research yielded stronger effect sizes using PND) PND = 95% | Fewer studies focused on other component skills of SD |
|                        |                                                               | Data = dependent variable | Calculated effect sizes | See other columns | Effect sizes and study coding (interrater reliability) | Average effect size = 1.38 (moderate gains in self-determination), median effect size .60 | Creating environments to use skills |
| Palmer et al. (2010)   | Literature review of current research re: self-determination | Transition across the Ages (Lawrence, KS): multi-page handout | To support individuals with | Figure 1: Life-Span View of Self-Determination Use of | | | |

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<tr>
<th>Author(s)</th>
<th>Study Title</th>
<th>Inclusion Criteria</th>
<th>Databases Searched</th>
<th>Conclusion</th>
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<tbody>
<tr>
<td>Cobb et al (2009)</td>
<td>Metasynthesis: review of 7 narrative and systematic reviews published since 2000 focusing on SD for individuals w/ disabilities</td>
<td>Inclusion criteria included within article</td>
<td>PsychInfo, Digital Dissertations and These and ERIC from 1997</td>
<td>Multicomponent self-determination interventions demonstrated greater positive effects than single-component interventions. Self-determination is teachable and valued by family. Reviews measuring academic qualities – SD intervention did not seem effective. Evidence of effectiveness of a multi-component intervention. Suggestions that future research focus on transitional outcomes (behavioral autonomy, self-regulation, psychological empowerment and self-realization) and not on academic outcomes.</td>
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</table>
**Search Question #2:** Is there evidence that the Cognitive Orientation to Occupation Performance (CO-OP) is an effective intervention for increasing independence with daily life tasks for youth with disabilities?

<table>
<thead>
<tr>
<th>Author and year of pub.</th>
<th>Type of report/Study design</th>
<th>Participant characteristics and selection</th>
<th>Site/context of study</th>
<th>Variables and Measures</th>
<th>Procedures</th>
<th>Key Findings</th>
<th>Application</th>
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<tbody>
<tr>
<td>Gharebaghy et al. (2015)</td>
<td>Experimental design single case</td>
<td>Multiple baselines</td>
<td>Iran</td>
<td>COPM, Goal Attainment Scaling, BOTMP, Raven Colored Progressive Matrices Test (human intelligence)</td>
<td>COPM for identifying 3 goals, GAS for specifying baseline and expected levels of goals. Phase A: baseline – no intervention (2 weeks for group one, and 3 and 4 weeks for groups 2 and 3). Phase B: all children received 12 intervention sessions (45-60 minutes) by trained OT. BOTMP performed 1x/week during intervention phase. COPM provided to both parents and children at end of intervention. GAS at end of intervention.</td>
<td>3 of 6 children had PND of 100% signifying highly effective intervention. 1 of 6 children – questionably effective (PND = 50%). 1 of 18 goals did not reach expected level on GAS</td>
<td>May improve motor problems of children with ADHD. Motor performance deficits cause difficulties with ADLs</td>
</tr>
<tr>
<td>Hyland (2012)</td>
<td>Secondary analysis of video tapes from two different studies:</td>
<td>University of Toronto</td>
<td>Each study had inclusion criteria</td>
<td>Secondary analysis of video tapes</td>
<td>Inter-rater reliability = 91%</td>
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<tr>
<td>Randomized, two-group clinic based trial (A)</td>
<td>(A) $n = 20$, mean age 9.05 Assigned to Contemporary Treatment approach (CTA) or CO-OP</td>
<td>Coding sheet for use with analyzing videos</td>
<td>Pre, 5th treatment and post-intervention sessions videoed</td>
<td>Descriptive statistics</td>
<td>Children are capable of generating DPAs which can be positively affected by CO-OP intervention</td>
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<tr>
<td>Randomized two group community-based trial: feasibility study (B)</td>
<td>(B) $n = 8$, between ages 8-12 Assigned to CO-OP or task-specific intervention (TSI)</td>
<td>All with identified motor coordination difficulties</td>
<td>All participants choose 3 areas to work on (motor goals)</td>
<td>Several one way ANOVAs calculated</td>
<td>CO-OP intervention has potential to improve participant’s ability to effectively identify a performance problem</td>
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<td>Post-test subjects in CO-OP group used more spontaneous DPAs which requires greater problem solving strategies then CTA and TSI group</td>
<td>Targeting development of client’s metacognition – “monitoring, evaluating and correcting one’s own performance while engaged in a task”</td>
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<td>Participants in CO-OP</td>
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<tr>
<td>Dawson et al. (2009)</td>
<td>Pilot study: single case study design</td>
<td>University of Toronto</td>
<td>Neuropsychological tests (pre-intervention only) measured attention, memory, executive function and intelligence</td>
<td>Dysexecutive Questionnaire (DEX) = daily life measure of executive dysfunction, 20-items, rated 5 point scale 0 = never, 4 = very often (max</td>
<td>Assessed pre-intervention, post-intervention and 3 month follow-up</td>
<td>2 of 3 participants showed significant improvement on DEX at post-intervention</td>
<td>CO-OP could be effective in improving performance with daily tasks in those with TBI and executive dysfunction</td>
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<td>3 adults with TBI and their significant others</td>
<td>Intervention took place in participant’s own environment (various community settings and home)</td>
<td>COPM</td>
<td>Sessions videotaped</td>
<td>CO-OP content altered to be more adult appropriate</td>
<td>20 sessions conducted, 2x/weekly for 10 weeks, sessions = 60 minutes long</td>
<td>Common problems affecting TBI population (attention, memory and executive functioning) may be amenable to intervention</td>
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<td>Recruited from community agency serving TBI population (C)</td>
<td>Sometimes conducted in office if needed</td>
<td>Dysexecutive Questionnaire (DEX) = daily life measure of executive dysfunction, 20-items, rated 5 point scale 0 = never, 4 = very often (max</td>
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</table>
There is benefit to problem-solving training and transfers to daily life tasks.

Importance of significant others to increase transfer across settings (benefit of parents being trained).

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Study Design</th>
<th>Sampling Method</th>
<th>Context</th>
<th>Measures</th>
<th>Outcome</th>
<th>Methodology</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phelan et al (2009)</td>
<td>Single case study design</td>
<td>Convenience sampling</td>
<td>High functioning Autism (HFA) or Asperger’s syndrome</td>
<td>Ages 7-14 years</td>
<td>N = 2, males, 9 years old w/ Asperger’s and 10-years-old, HFA</td>
<td>Screening measures: Movement Assessment Battery for Children (M-ABC) &amp; parental questionnaire</td>
<td>Visual analysis of graphed PQRS data performed.</td>
</tr>
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</table>

score 80).
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<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Recruitment</th>
<th>Intervention Details</th>
<th>Outcome Measures</th>
<th>Analysis</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polatajko et al. (2012)</td>
<td>Pilot randomized controlled trial</td>
<td>Recruited using Cognitive Rehabilitation Research Group database OR discharged from Rehabilitation Institute of St. Louis&lt;br&gt;N = 20&lt;br&gt;Standard OT (SOT) group = 9 (5 withdrew, n =4)&lt;br&gt;CO-OP group = 11 (7 withdrew, n = 4)&lt;br&gt;Population experiences dependence with ADLs and participation</td>
<td>Community based intervention&lt;br&gt;Video at baseline, during all 10 sessions and at end COPM completed by parents</td>
<td>COPM&lt;br&gt;PQRS&lt;br&gt;Administered both before and after intervention</td>
<td>Means and standard deviations were calculated for both main outcomes&lt;br&gt;U scores were used to compare between-group change scores&lt;br&gt;Simple linear regression analysis</td>
<td>CO-OP participants showed greater improvement in PQRS and in COPM performance compared to SOT&lt;br&gt;No group differences in COPM satisfaction between groups</td>
</tr>
</tbody>
</table>
| Missiuna et al. (2010) | Pre- to post-intervention study | Children with acquired brain injury  
Between ages 6-15 years old  
Scored lower than 5 on 2 or more sections of SFA  
N = 6  
Moderate brain injury  
6-19 months post-injury only receiving CO-OP | Ontario, Canada – participants had been admitted to tertiary care center, and participating in longitudinal study called “Transitions Study”  
Children brought to clinic weekly or sessions conducted at home if needed | Outcome measures taken pre-intervention, post-intervention and 4 month follow-up  
COPM  
PEGS  
PQRS  
Vineland Adaptive Behavior Scales  
Therapist kept session logs | Pre:  
VABS done with parents over phone  
OT used COPM or PEGS to select three target tasks  
COPM with parents  
Baseline data obtained by observation of video of child performing each task  
Intervention, all children received CO-OP for 10 weeks, 1x/week for 1 hour  
Video of first session, randomly selected session and final treatment  
Post – 1 week post intervention, video tape of child doing task, COPM and VABS done again.  
4 month follow-up: post-intervention | Visual inspection showed consistent pattern improvement across both outcome measures  
ANOVA showed significant improvement for performance  
Mean PQRS scores showed improvement in functional performance after intervention and at 4 month follow-up  
Improvement on VABS suggests children were able to generalize skills to other tasks/settings  
Parent and caregiver participation was important | CO-OP intervention may be effective with children with ABI (that experience cognitive, behavioral, motor and psychosocial deficits) |
<p>| Skidmore et al. (2011) | Case report, limited generalization | Pilot study to test feasibility of using CO-OP in inpatient rehab setting | Stroke with cognitive impairments | 31-year-old college-educated European American w/ mild to moderate severe embolic stroke | Poor awareness of deficits | Inpatient stroke rehab at academic health center | Descriptive measures: National Institutes of Health Stroke Scale (NIHSS) Repeatable Battery Assessment of Neuropsychological Status Delis-Kaplan Executive Functioning Systems Chedoke McMaster Assessment Impairment Inventory Hamilton Rating Scale for Depression | CO-OP intervention in one 45 minute session per day, 5 days/week for length of inpatient stay (14 days) in addition to other acute rehab therapies Workbook activities Progressed to more goals as sessions progressed Participant’s spouse participated in first 3 sessions | Changes in ADL disability (PASS and FIM) were clinically meaningful Positive feedback from participant and participant’s spouse | Those with executive functioning deficits (attention, visuospatial function and delayed memory) may be able to learn and apply meta-cognitive strategy to daily activities | conducted again | Graphs ANOVA |
| McEwen et al. (2015) | Exploratory, single-blind, RCT | N = 35 randomized, 26 completed intervention | Participants referred to outpatient stroke rehab programs at 2 university-affiliated, freestanding rehab centers (Toronto or St. Louis) | PQRS COPM Stroke Impact Scale Participation Domain Community Participation Index Self-Efficacy Gauge | Baseline assessment OT conducted goal-setting interview with COPM, selected 4-6 goals Baseline video performing self-selected activity goals Both groups received usual outpatient stroke rehab CO-OP group received max of 10 sessions of CO-OP 2x/week for 45 minutes CO-OP and 45-60 | Descriptive statistics (change scores and SD) CO-OP had medium effect size for PQRS trained activities over usual care and large for PQRS untrained activities at Time 2 Time 3: large effects change scores were found for both PQRS trained and untrained activities | Demonstrates potential for transfer of cognitive strategy training to new skills, untrained activities for those with stroke CO-OP had a medium effect on self-efficacy and therefore CO-OP may improve self-efficacy, which then mediates |</p>
<table>
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<tr>
<th>minutes for usual care group</th>
<th>over usual care transfer of skills.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outcome measures conducted at Time 1 (pre), Time 2 (discharge from OT or after 10 sessions) and Time 3 (3 months after Time 2)</td>
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</table>
Appendix C: Logic Model: Becoming Responsible: Transitioning to Adulthood

**Program Clients**
Parents of youth with disabilities (any diagnosis) ages 9-22 in the Boston area for pilot phase
Service organizations and local private schools

**Program Resources**
Staffing- main author to manage web site
Online platform- domain name purchased
Funding- Costs to design and maintain the website, dissemination efforts.
Local service agencies: Easter Seals, Boston University Occupational Therapy Department, The Cotting School, Perkins School for the Blind, Koomar Center.

**Inputs Resources**

**Problem Theory**
Bronfenbrenner’s ecological model of human development: emphasis on the proximal processes in the bidirectional relationship between parent and child on development.
Interactions must take place on a regular basis with consistency in increasingly complex to assist with development.

**Nature of the Problem**
- Youth with disabilities do not make as successful of a transition to adulthood as youth without disabilities.
- Parents raising children with disabilities experience more stress compared to parents raising children without disabilities.
- There are limited resources addressing this problem.

**Interventions and Activities**
Goal setting tasks using modified PEDI Responsibility Scale.
Problem-solving strategies
Activities based on the Cognitive Orientation to Daily Occupational Performance Problems (CO-OP) and the Self-Determined Learning Model of Instruction.
Activities are translated for use by parents into printable worksheets.

**Program Outputs**
Number of parents participating
Number of hours spent reading materials
Numbers of hours spent directly utilizing strategies

**Nature of the Problem**
Intermediate Outcomes
- Decrease in caregiver burden
- Increased independence in youth

Long-Term Outcomes
- Increased independence in post-high school life (better transition to adulthood as measured by educational attainment, competitive employment, residential independence, family formation)

**Activities Outputs**

**Interventions and Activities**
- Increased assumption of responsibility by the child
- Increase in score on modified PEDI Responsibility Scale
- Increased independence in youth
- Parent satisfaction
- Parent accessibility
- Feasibility of time use with materials

**Outcomes**

**External/Environmental Factors:** (facility issues, economics, public health, politics, community resources, or laws and regulations)
1) Logistics and regulations of online parent resource. 2) Funding (domain name, dissemination efforts). 3) Community organizations that use the program. 4) Availability of main author to contact those with questions when utilizing the program.
Appendix D: Executive Summary

Becoming Responsible: Transitioning to Adulthood seeks to facilitate the transfer of responsibility for daily life tasks from parents to their children with disabilities. The program seeks to address the difference in successful transitioning to adulthood between youth with disabilities and their peers without disabilities. This discrepancy has been documented in the research (Wells, Sandefur, & Hogan, 2003; Friedman, DeLucia, Holmbeck, Jandasek & Zebracki, 2009; Frisch, 2013). Parents of this population experience more stress and expressed that the ongoing focus on caregiving tasks day to day make it difficult for them to develop and implement plans for their children’s future independence (Respler-Herman, Mowder, Yasik & Shamah, 2012; Timmons, Whitney-Thomas, McIntyre, Butterworth & Allen, 2004).

Bronfenbrenner’s bioecological model of human development was used as the socio-cultural lens in which to view both the problem and the potential solution, namely the development of the Becoming Responsible: Transitioning to Adulthood program (Bronfenbrenner & Morris, 2006). Bronfenbrenner’s model explains development as the interaction between the developing individual and his or her environment. Specifically, the proximal processes that take place between the parent and developing child are the most essential to the development of this program. Most importantly, “to be effective [in influencing development], the interaction must occur on a fairly regular basis over extended periods of time” and must be a “progressively more complex reciprocal interaction” (Bronfenbrenner & Morris, 2006, p. 797). Given the lack of available research on the specifics of transferring responsibility for daily life tasks from parent to
child, a program addressing this area may be influential on increasing successful transition to adulthood.

After conducting a thorough review of the literature to explore evidence-based approaches taken to address the discrepancy between transition outcomes for youth with disabilities and those without, two widely researched interventions were synthesized into the development of this new program. The two interventions are: The Self-Determination Learning Model of Instruction (SDLMI) and the Cognitive Orientation to daily Occupational Performance (CO-OP). The SDLMI was developed for use by special education providers in the school setting for students with intellectual disabilities, but had been translated for use in the home setting for parental use (Palmer & Wehmeyer, 2002). The SDLMI uses three phases consisting of four problem-solving questions to assist the student from where they are to where they want to be in respect to a educational goal (Wehmeyer, 2007).

The CO-OP is an occupational therapy intervention that was initially developed for children with developmental coordination disorder (DCD); however, since development, it has been, “used widely with neurological and adult populations and across different types of dysfunction” (AOTA, 2013, S23) including; Attention Deficit Hyperactivity Disorder (ADHD), Acquired brain injury (ABI), Autism, adult traumatic brain injury (TBI) and the adult stroke population. Furthermore, CO-OP “is a client-centered, problem-solving, performance-based intervention that facilitates performance acquisition through a process of guided discovery of strategies that enable learning of skills” (AOTA, 2013, p. 19).
Both interventions have been researched to show effectiveness (Cobb, Lehmann, Newman-Gonchar & Alwell, 2009; Wehmeyer, 2013; Palmer, Wehmeyer, Shogren, Williams-Diehm & Soukup, 2012; Shogren, Palmer, Wehmeyer, Williams-Diehm & Little, 2012; Wehmeyer, Shogren, Palmer, Williams-Diehm, Little & Boulton, 2012; Wehmeyer, Palmer, Shogren, Williams-Diehm & Soukup, 2013; Powers et al., 2012; Algozzine Browder, Karvonen, Test & Wood, 2001; Mazzotti, Test & Wood, 2013; Hyland, 2012; Phelan, Steinke & Mandich, 2009; Gharebaghy, Rassafiani & Cameron, 2015; Polatajko, McEwen, Ryan & Baum, 2012; Missiuna et al., 2010; Dawson, Gaya, Hunt, Levine & Polatajko, 2009). Furthermore, some research suggests that the combination of the SDLMI and another intervention with multiple components and instructional methods may be more effective in increasing self-determination in youth with disabilities (Palmer et al., 2012; Wehmeyer et al., 2013; McDougall, Evans & Baldwin, 2010; Powers et al., 2012; Cobb et al., 2009).

_Becoming Responsible: Transitioning to Adulthood_ builds on these existing interventions, their research and synthesizes them into a web-based manual for parents. The website includes an introduction to the content of the program and how to utilize the resources. The program includes worksheets and instructions to be filled out in collaboration with their child. First, the parent completes the modified version of the Pediatric Evaluation of Disability Index (PEDI) Responsibility domain to identify potential areas for the parent and child to work on together. The parent uses the information to have a conversation with the child on goal setting. Subsequently, the parent and child move through the four phases of the program from Phase 1: GOAL,
Phase 2: PLAN, Phase 3: DO and Phase 4: CHECK. First, the parent teaches their child about the Type 1 Strategy (GOAL-PLAN-DO-CHECK) which can be applied to any problem-solving situation. Secondly, the parent performs an analysis of their child’s performance of the task (the goal) to identify performance breakdowns and to develop potential domain specific strategies or Type 2 Strategies, which relate to only one area of dysfunction (i.e. verbal mnemonic to recall sequence of steps while depositing a check in the bank) (Polatajko & Mandich, 2004). The parent uses teaching techniques of direct teaching, modeling, and fading to further transfer responsibility for the identified goal. The parent continues to encourage the use of strategies and logs their child’s success to promote their child’s ability to self-evaluate progress towards goal. The child/teen is encouraged to track progress with the goal using their own log form.

The program will be evaluated in two phases. The first phase of the evaluation will be a small-scale pre-post test study (n = 5–10). Parents will be recruited from two local, private special education schools. Parents recruited will received two copies of the modified version of the PEDI Responsibility domain to complete at the beginning (prior to implementing the program) and once at 6-months. These parents will agree to participate in an in-depth telephone interview to gather qualitative information for program improvements. The second phase will be implemented following program improvements, and will be conducted on a larger scale (n = 30) with parents recruited from various geographical areas. Parents will be mailed 3 copies of the modified version of the PEDI Responsibility domain for completion at the beginning (prior to implementing the program), at 6-months and at 12-month follow-up. Furthermore,
parents will be provided a link to complete a survey at 12-months to assess satisfaction and accessibility of the program. This survey will also offer an opportunity to answer open-ended questions to gather more qualitative information. The main author will complete data collection, secure storage and analysis.

Hopefully, the program evaluation will demonstrate the value of the Becoming Responsible: Transitioning to Adulthood program. The program values the role of parents in the proximal processes of development. The flexible nature of the program allows parents to make decisions regarding the best way to present the information and utilize the strategies. Implementing this program in the home setting, may facilitate the transfer of skills between home and school by improving communication between parents, children and special education providers and related services, including occupational therapy. The program reflects the interactive nature between the developing individual, the environment in which they live and the occupations in which they participate. Providing parents with this resource may decrease caregiver stress, improve social-emotional relationships between parent and child and increase successful transitions to adulthood for youth with disabilities.
References


Appendix E: Supportive Documents

How do I organize this program on my own?

1. It might be helpful to print out all the worksheets before using this program.

2. Organizing the worksheets in a 3-ring binder based on the 4 phases might be a helpful way to keep track of everything.

   a. Phase 1: GOAL
      i. Taking Care of Yourself: HOME
      ii. Taking Care of Yourself: COMMUNITY
      iii. How do I talk to my child and teen about goals?
      iv. Phase 1 flow chart, worksheets and examples

   b. Phase 2: PLAN
      i. Phase 2 flow chart, worksheets and examples
      ii. Type 2 Strategies
      iii. Observation Worksheet
      iv. Guided Discovery Worksheet

   c. Phase 3: DO
      i. Phase 3 Flow chart
      ii. Phase 3 Parent Form
      iii. Phase 3 Child/Teen Form

   d. Phase 4: CHECK
      i. Phase 4 flow chart, worksheets and examples

Examples are provided to help you complete the worksheets, but you can make decisions on your own about how much to rely on them.
How do I talk to my child and teen about goals?

Here are some helpful hints on how to talk to your child about goals and goal setting.

- Write down areas that you would like your child and teen to work on.
- Start the conversation by focusing on your child’s and teen’s interests
  - “I know you like to help me in the kitchen. Is there something I do in the kitchen that you would like to help more with?”
  - “What things do you like to help with around the house?”
  - “Is there something you like to do around the house that you want to be better at doing?”
  - “Is there something I or someone else does around the house that you’d like to learn to do?”
- Listen to your child and teen.
- Write down what your child and teen says.
- Ask your child and teen what a goal is
  - “What does the word ‘goal’ mean to you?”
  - “Have you ever set a goal before?”
- Explain to your child and teen what a goal is
  - “A goal is having something to work on so you can do something better. For example, I want to drink more water everyday, so that is my goal. [Or use another example that is relevant for you.] When you set a goal, you have to decide how you can change the way you do things so you can meet your goal.”
- Ask your child and teen to now explain what a goal is in their own words to make sure they understand. If they still seem unclear, think about whether you can use an example from his or her recent experience of learning a new skill or improving something.
- Now pull out the Phase 1 Goal setting worksheet to complete.

What to do if your child/teen has trouble answering the questions on the worksheets?

Here are some tips on what to do.

1. Try to change the wording of the question to make it easier to understand. You know your child/teen best and how they communicate.
2. Give an example of an answer.
3. If your child/teen continues to have trouble or continues to answer “I don’t know” ask them “What do you know about this right now?”
4. Give your child/teen enough time to think of answer. Going through the phases the first time will take longer.
5. Keep track of which questions your child/teen has trouble with so that the next time you go through the worksheets with another goal, you can use the strategies or wording that helped them to answer it.
6. Your child/teen may be having trouble because the goal is too big and has too many parts. You may want to break the big goal into smaller parts to make it more achievable and easier to think about. If the goal is too big, then there will most likely be many barriers to identify and more solutions to develop to overcome the barriers.
   a. Example: Your child/teen wants to get ready for school on time, but that morning routine includes a lot of activities. Maybe it would be easier to only start with getting dressed on time. Focusing in on this part of the morning routine may make the goal more achievable. The next time going through the phases, your child/teen could add making breakfast on time.
Phase 1: GOAL
Flow Chart

This flow chart is to help you figure out how to support your child/teen while asking questions and developing answers. Use this chart with the “How do I talk to my child and teen about goals? Worksheet.”

<table>
<thead>
<tr>
<th>Child/Teen task:</th>
<th>Parent Supports:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem to solve:</td>
<td>Explore interests, abilities and learning style</td>
</tr>
<tr>
<td>What is my goal?</td>
<td>Talk about Modified PEDI results</td>
</tr>
<tr>
<td></td>
<td>Offer choices</td>
</tr>
</tbody>
</table>

**Question 1:** What do I want to work on?

**Parent Objectives Q1:**
- Help your child identify things they are good at and how they learn best
- Let your child have choices and talk about interests, values and beliefs
- Talk with your child about what is important

**Question 2:** What do I know about it now? How do I do it now?

**Parent Objectives Q2:**
- Help your child understand how they do it now and how they need to do it to meet their goal
- Help your child think about the environment and what is helpful and what gets in the way of meeting the goal

**Question 3:** What do I have to do to meet my goal?

**Parent Objectives Q3:**
- Help your child focus on what actions to consider (modifying environment, or learning something new)

**Question 4:** What can I do to make this happen?

**Parent Objectives Q4:**
- Help your child to choose a goal and what it will look like when it is met.
Phase 1: GOAL Worksheet
Taking Care of Yourself: HOME

You and your child or teen complete this worksheet together.

1. What do I want to work on or do better when ____________________?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

2. What has to happen in order for me to ____________________________?

________________________________________________________________________
________________________________________________________________________

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<thead>
<tr>
<th>What has to happen?</th>
<th>What happens now?</th>
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</tbody>
</table>

3. What do I have to do to meet my goal of ____________________________?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
4. What can I do to make this happen?
Phase 1: GOAL Worksheet
Taking Care of Yourself: HOME

EXAMPLE

You and your child or teen complete this worksheet together.

1. What do I want to do work on when getting ready for the day?

   Getting dressed and being on time

2. What has to happen in order for me to get dressed and be on time?

   I need to get my clothes and put them on in time so I don’t miss the bus.

<table>
<thead>
<tr>
<th>What has to happen?</th>
<th>What happens now?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I need to get my clothes</td>
<td>I can’t decide what to wear</td>
</tr>
<tr>
<td>I need to put them on in time</td>
<td>Sometimes I’m not ready and I miss the bus</td>
</tr>
<tr>
<td>so I don’t miss the bus.</td>
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</tr>
</tbody>
</table>

3. What do I have to do to meet my goal of getting dressed on time?

   Find out what time the bus comes
   Decide what to wear

4. What can I do to make this happen?

   Wake up earlier
   Pick out clothes ahead of time (night before)
   Check the time
Phase 1: GOAL Worksheet  
Taking Care of Yourself: COMMUNITY  

EXAMPLE  

You and your child or teen complete this worksheet together.  

1. What do I want to work on or do better when managing my money?  

   Saving money  

2. What has to happen in order for me to save my money?  

   I need to put my money in the bank.  

<table>
<thead>
<tr>
<th>What has to happen?</th>
<th>What happens now?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spend less money</td>
<td>Keep my money in my piggy bank in my room</td>
</tr>
<tr>
<td>Make it hard to get to</td>
<td>I take money out every week</td>
</tr>
</tbody>
</table>

What do I have to do to meet my goal of managing my money?  

   Spend less money  

What can I do to make this happen?  

   Keep track of money I spend
Phase 1: GOAL Worksheet
Taking Care of Yourself: COMMUNITY

You and your child or teen complete this worksheet together.

1. What do I want to work on or do better when ______________________?

2. What has to happen in order for me to __________________________?

<table>
<thead>
<tr>
<th>What has to happen?</th>
<th>What happens now?</th>
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</tbody>
</table>

3. What do I have to do to meet my goal of ______________________?

______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________
4. What can I do to make this happen?
Phase 2: PLAN
Flow Chart
This flow chart is to help you figure out how to support your child/teen while asking questions and developing answers for making a plan.

<table>
<thead>
<tr>
<th>Child Problem to Solve:</th>
<th>Parent Support:</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is my plan?</td>
<td>Self-scheduling</td>
</tr>
<tr>
<td></td>
<td>Self-instruction</td>
</tr>
<tr>
<td></td>
<td>Antecedent cue regulation</td>
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<tr>
<td></td>
<td>Offer choices</td>
</tr>
<tr>
<td></td>
<td>Teach problem-solving</td>
</tr>
<tr>
<td></td>
<td>Self-advocacy training</td>
</tr>
<tr>
<td></td>
<td>Communication skills training</td>
</tr>
<tr>
<td></td>
<td>Self-monitoring</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 1: What can I do/change to make my plan better?</th>
<th>Parent Objectives Q1:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Help your child think about how he/she does it now and how far they have to go to meet their goal</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 2: What could stop me from doing it? ROAD BLOCKS!</th>
<th>Parent Objectives Q2:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Help your child to develop a plan to bridge gap between where he or she is now and where they want to be to meet the goal</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 3: What can I do to take away the road blocks in my way?</th>
<th>Parent Objectives Q3:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Team up with your child to find out what is getting in the way of doing it, what can he or she do to change these things</td>
</tr>
<tr>
<td></td>
<td>Talk with your child to decide what your role is</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 4: When will I start my plan?</th>
<th>Parent Objectives Q4:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Help your child schedule an action plan – making a timeline</td>
</tr>
<tr>
<td></td>
<td>Help your child to make an action plan</td>
</tr>
<tr>
<td></td>
<td>Help your child learn how to self-monitor</td>
</tr>
</tbody>
</table>
Phase 2: PLAN Worksheet
Taking Care of Yourself: HOME

You and your child or teen complete this worksheet together.

What is my plan? Let’s think about how to reach the goal that you set.

What can I do/change to make my plan better?

What could stop me from doing it? (ROAD BLOCKS)

What can I do take away the ROAD BLOCKS in my way?

When will I start my plan?

END OF PHASE 2.
I will start working on my plan in Phase 3 to keep track of how my plan is working and then go on to Phase 4.
Phase 2: PLAN Worksheet
Taking Care of Yourself: HOME

Example

What is my plan? Let's think about how to reach the goal that you set.

My goal is: getting dressed and being on time for the bus.

Wake up earlier
Pick out clothes night before
Ask for help

What can I do/change to make my plan better?

Ask what time the bus comes
Find out what to wear

What could stop me from doing it? (ROAD BLOCKS)

Having trouble getting dressed
Waking up late

What can I do to take away the ROAD BLOCKS in my way?

Ask for help getting dressed
Setting an alarm

When will I start my plan?

Monday

END OF PHASE 2.
I will start working on my plan in Phase 3 to keep track of how my plan is working and then go on to Phase 4.
Phase 2: PLAN Worksheet
Taking Care of Yourself: COMMUNITY

You and your child or teen complete this worksheet together.

What is my plan? Let’s think about how to reach the goal that you set.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

What can I do/change to make my plan better?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

What could stop me from doing it? (ROAD BLOCKS)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

What can I do take away the ROAD BLOCKS in my way?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

When will I start my plan?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

END OF PHASE 2.
I will start working on my plan in Phase 3 to keep track of how my plan is working and then go on to Phase 4.
Phase 2: PLAN Worksheet
Taking Care of Yourself: COMMUNITY

EXAMPLE

You and your child or teen complete this worksheet together.

What is my plan? Let's think about how to reach the goal that you set.

- Keep track of money spent
- Spend less money

What can I do/change to make my plan better?

- Talk to bank about saving money

What could stop me from doing it? (ROAD BLOCKS)

- Forgetting to write down what I spend

What can I do take away the ROAD BLOCKS in my way?

- Write it down in journal (or on iPad)

When will I start my plan?

- Tomorrow at the store

END OF PHASE 2.

I will start working on my plan in Phase 3 to keep track of how my plan is working and then go on to Phase 4.
**Observation Worksheet:**

**Things to consider before your child does the task:**

1. Does your child want to do the task?
   - **NO** → STOP! It is important that your child wants to do the task and is motivated by it.
   - **YES**, move on to Question #2

2. Does your child, in general, know what to do?
   - **NO** → STOP! It is important that your child knows what to do so that they can be safe with it.
   - **YES**, move on to Question #3

Now have your child do the task: Remember, pay attention to the task itself, your child and the environment (things around him/her)! All 3 work together for success!

3. Did your child do the task completely and do a good job with it?
   - **YES** → Choose a different task/goal!
   - **NO**, move on to Question #4

4. During the task, what issues does your child come across? (For common issues to consider see **Performance Issue Chart**). Make sure you write the issues down on a piece of paper to keep track! You might have to do this a few times to make sure you catch all the issues. There is a lot to look at! Be sure to ask your child what they think is hard to do too!

   For each issue you noticed during the task:

   a. Does your child know what to do to overcome the issue? Can they solve the problems they face?
      - **NO** → Start developing goals and strategies!
      - **YES**, move on to b.

   b. Does your child want to do that part of the task even if they are having trouble?
      - **NO** → It is important your child wants to do it.
      - **YES**, move on to c.
c. Can your child do the task?
   **NO**→ Move on to next questions. If you answer **NO** to any of them, start Phase 2: Planning!
   
   i. Is your child able to do the task (cognitively, physically, etc.)?
   
   ii. Is the task appropriate for your child to do?
       Is it too hard? Is it safe?
   
   iii. Is the environment appropriate for your child to do the task? (i.e. the countertop is the right height for your child to safely cook eggs; is there enough light to see what he/she is doing; is the television on in the background and distracting your child)

   If you answer **YES** to all of them, then you need to choose another task/goal to focus on, because it seems like your child is able to do the task on their own without a problem!
Guided Discovery Worksheet

Parent completes this task.

1. Think about the task from beginning to end.
2. Write down the things your child/teen needs to do to complete the task
3. Write down all the steps and make them short, straightforward phrases your child/teen will understand. This way you will have phrases already prepared to help your child/teen move from one step to the next during the task.

See example below for the task of doing laundry.

1. THINK ABOUT TASK BEGINNING TO END
2. Things you need to do laundry:
   a. Laundry
   b. Laundry basket
   c. Soap
3. Write down the steps of the task into short phrases:
   a. Get your laundry in the basket.
   b. Bring it to the laundry room.
   c. Separate clothes into two piles (light and dark).
   d. Open machine.
   e. Measure soap.
   f. Pour in soap.
   g. Put in dark OR light clothes.
   h. Close machine.
   i. Turn dial to star sticker (verbal cues) and press ‘Start.’ (Star sticker)
<table>
<thead>
<tr>
<th>Performance Issue identified during Observation</th>
<th>Type 2 Strategies</th>
<th>Examples of what to say:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your child doesn’t know enough about the task to participate in goal setting or planning</td>
<td>Provide more information to increase the child’s knowledge of the task</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Talk about the specifics of the task, parts of the task, potential modifications to the task or parts of the task</td>
<td>“Let’s use the pictures to get [dressed]!”</td>
</tr>
<tr>
<td></td>
<td>Help your child increase attention to his/her body, how to shift the body in relation to completing the task</td>
<td>(Picture guide can be used with many tasks)</td>
</tr>
<tr>
<td></td>
<td>Modify the task</td>
<td>“Let’s start with picking out your clothes”</td>
</tr>
<tr>
<td></td>
<td>Help your child increase attention to his/her body, how to shift the body in relation to completing the task</td>
<td>“Let’s sit down to put on your pants!”</td>
</tr>
<tr>
<td>Your child knows what needs to be done, but cannot do the task</td>
<td>Modify the task</td>
<td>“I’ll tie up the trash bag, but I want you to put it in the garage bin”</td>
</tr>
<tr>
<td></td>
<td>Help your child increase attention to his/her body, how to shift the body in relation to completing the task</td>
<td>“Carry the trash bag with two hands”</td>
</tr>
<tr>
<td></td>
<td>Tell your child to pay attention to the feeling of a particular movement</td>
<td>“Feel the strings pull tight when you tie up the trash bag”</td>
</tr>
<tr>
<td></td>
<td>Attention to doing: direct your child’s attention to the part of the task that needs to be monitored</td>
<td>“Make sure the top of the bag is closed.”</td>
</tr>
<tr>
<td>Your child can do the task but needs support while doing it</td>
<td>Modify the task</td>
<td>“Remember to use your checklist”</td>
</tr>
<tr>
<td></td>
<td>Provide hints and cues to your child for the steps needed to be done</td>
<td>“Do you see where your card should go in?”</td>
</tr>
<tr>
<td></td>
<td>Encourage your child to use self-talk while performing task</td>
<td>“Let’s try saying the steps out loud.” “Now I will enter my PIN number. Then I choose deposit.”</td>
</tr>
<tr>
<td></td>
<td>Use a pattern of 4–5 clear, easy words that are meaningful to your child and the task to help guide a sequence of movements. Repeat these each time your child does the task in the future to help him/her remember.</td>
<td>“Card, Choose, Do, Put away!”</td>
</tr>
</tbody>
</table>

Phase 3: DO
Flow Chart

Have your child/teen do the task chosen as a goal in Phase 1 using the plan identified in Phase 2.

Parent Supports:
Review all worksheets first.
1. Observation Worksheet
2. Common Performance Problems
3. Guided Discovery Worksheet
4. Type 2 Strategies Chart

Have your child/teen do the task a few times over the course of a week.

Parent Objectives:
Encourage self-talk of your child/teen.
Continue to identify Type 2 Strategies.
Remember 4 rules:
  Coach, don’t adjust!
  Make it obvious!
  Ask, don’t tell!
  One thing at a time!
Phase 3: DO
Parent Form

EXAMPLE

- Use this worksheet to keep track of observations you make as your child or teen puts the plan to use during tasks.
- Keep encouraging use of strategies.
- Keep track of success and continue to identify areas where your child or teen has problems.

There is also another Phase 3: DO Worksheet for your child or teen to complete if appropriate. You could have them keep track of strategy use with checklist or stars. Help them by filling in the My Goal Section of the paper, and encourage them to keep track of when they do the task well.

You could think about giving your child a reward for weeks when they complete the task successfully a certain amount of times. (Example: Child gets on the bus on time every day for one week. Gets to choose a movie to watch Friday night (or whatever is motivating for your child).

<table>
<thead>
<tr>
<th>Task</th>
<th>Observations</th>
</tr>
</thead>
</table>
| Getting ready in the morning on time to get on the bus | • Needs to be reminded to set alarm clock  
  o Maybe put a stick note on bedside table as reminder |
| Setting alarm clock                              | • Forgets the steps to set the alarm clock                                  |
| Laying out clothes                               | • Chooses wrong clothes for the weather  
  o Talk about weather the night before  
  o Picture prompts for clothing choices based on weather (i.e. winter, spring, summer, fall) |
### Phase 3: DO
Child/Teen Form

#### Example

I get a star when I do my plan well.

<table>
<thead>
<tr>
<th>My goal</th>
<th>Stars</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting on the bus on time</td>
<td></td>
</tr>
<tr>
<td>Setting alarm clock at night</td>
<td></td>
</tr>
<tr>
<td>Picking out clothes the night before</td>
<td></td>
</tr>
</tbody>
</table>
Phase 4: CHECK
Flow Chart

This flow chart is to help you figure out how to support your child/teen while asking questions and developing answers to decide if the goal is met.

Child/Teen Problem to Solve:
What did I learn?

Parent Supports:
Self-evaluation strategies
Offer choices
Teach goal-setting
Self-reinforcement strategies
Self-recording strategies
Self-monitoring

Question 1: What did I do that was good? What did I do that was not good?

Parent Objectives Q1:
Help child to self-evaluate progress towards goal

Question 2: What ROAD BLOCKS did I take away? How did I do that?

Parent Objectives Q2:
Talk with child to help him or her compare progress with goal.
Help child/teen figure out what road blocks were removed.

Question 3: What can I do now?

Parent Objectives Q3:
Help re-evaluate goal if child is not making good progress
Help determining if need to change goal or keep the same
Help identify if action plan is working or not work
Help child to change action plan if needed

Question 4: Did I reach my goal?

Parent Objectives Q4:
Help child understand if goal has been achieved
Find out how the child feels about the goal and what has been learned
Phase 4: CHECK Worksheet
Taking Care of Yourself: HOME

You and your child or teen complete this worksheet together.

What have I learned? Let’s think about whether you achieved your goal or not.

________________________________________________________________________

________________________________________________________________________

What did I do that was good? What did I do that was not good?

<table>
<thead>
<tr>
<th>Helped</th>
<th>Didn’t Help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What ROAD BLOCKS did I take away? How did I do that?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

What can I do now?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Did I reach my goal?

Yes ___ X ___  No_______

YES - how do you feel about what you did?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Now go back to Phase 1 and set a new goal. Good job!

NO - I will look at Phase 1 again. If the goal is still a good one for me, I will move on to phase 2 to make a new plan. Or I will make a new goal.
Phase 4: CHECK Worksheet
Taking Care of Yourself: HOME

EXAMPLE

You and your child or teen complete this worksheet together.

What have I learned? Let's think about whether you achieved your goal or not.

The bus comes at 8:10 AM.
I need to wake up at 7 AM to have enough time.

What did I do that was good? What did I do that was not good?

Waking up earlier
Keeping track of time
Picking out clothes night before

<table>
<thead>
<tr>
<th>Helped</th>
<th>Didn't Help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waking up earlier</td>
<td>Forgetting to set my alarm</td>
</tr>
<tr>
<td>Keeping track of time</td>
<td>Not asking for help if I need it</td>
</tr>
<tr>
<td>Picking out clothes night before</td>
<td></td>
</tr>
</tbody>
</table>

What ROAD BLOCKS did I take away? How did I do that?

Road block: Sleeping late by setting my alarm

What can I do now?

I get dressed in time to get on the bus.

Did I reach my goal?

Yes ___X___  No_____

YES - how do you feel about what you did?

I am happy to get dressed on my own and get on the bus for school.
Now go back to Phase 1 and set a new goal. Good job!

**NO** - I will look at Phase 1 again. If the goal is still a good one for me, I will move on to phase 2 to make a new plan. Or I will make a new goal.
Phase 4: CHECK Worksheet
Taking Care of Yourself: COMMUNITY

You and your child/teen complete this together.

What have I learned? Let’s think about whether you achieved your goal or not.

_________________________________________________________

_________________________________________________________

_________________________________________________________

What did I go that helped? What did I do that did not help?

<table>
<thead>
<tr>
<th>Helped</th>
<th>Did not help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

What ROAD BLOCKS did I take away? How did I do that?

_________________________________________________________

_________________________________________________________

_________________________________________________________

What can I do now?

_________________________________________________________

_________________________________________________________

_________________________________________________________

Did I reach my goal?

YES _X_  NO _____
**YES** - how do you feel about what you did?

Now go back to Phase 1 and set a new goal! Good job!

**NO** - I will look at Phase 1 again. If the goal is still a good one for me, I will move on to phase 2 to make a new plan. Or I will make a new goal.
Phase 4: CHECK Worksheet
Taking Care of Yourself: COMMUNITY

EXAMPLE

What have I learned? Let’s think about whether you achieved your goal or not.

To write down what I spend money on.

What did I go that helped? What did I do that did not help?

<table>
<thead>
<tr>
<th>Helped</th>
<th>Did not help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Called the bank for help on how to save money.</td>
<td></td>
</tr>
<tr>
<td>Set-up bank account to save money.</td>
<td></td>
</tr>
</tbody>
</table>

What ROAD BLOCKS did I take away? How did I do that?

My roadblock was having a hard time keeping track of my money. I took away that roadblock by remembering to write down what I spend.

What can I do now?

Now I have a bank account to save money in.

Did I reach my goal?

YES _X_ ______________ NO_____

YES - how do you feel about what you did?

I am happy to save money. I can now save money for new bike.
Now go back to Phase 1 and set a new goal! Good job!

**NO** - I will look at Phase 1 again. If the goal is still a good one for me, I will move on to phase 2 to make a new plan. Or I will make a new goal.
References


Curriculum Vitae

PERSONAL

Name                Colleen Margaret Young

Year and Place of Birth       1990
                                Framingham, Massachusetts

Address               333 Ricciuti Drive
                        Unit #2234
                        Quincy, Massachusetts 02169
                        508-541-7658 (phone)
                        youngcol@bu.edu

FORMAL EDUCATION

O.T.D.                           Boston University, Boston, MA 02215  1/2016
                                Major: Doctor of Occupational Therapy

M.S.                             Boston University, Boston, MA 02215  1/2014
                                Major: Master of Science: Occupational Therapy

B.S.                             Boston University, Boston, MA 02215  5/2012
                                Major: Bachelor of Science: Therapeutic Studies

CREDENTIALS

Registered Occupational Therapist by the National Board for Certification in Occupational Therapy (NBCOT)

LICENSED

Licensed Occupational Therapist, Commonwealth of Massachusetts

POSITIONS HELD

2014 to date  Occupational Therapist: New England Sinai Hospital
                        Staff Occupational Therapist responsible for evaluation, intervention and
discharge planning for patients of different ages that are experiencing
various illnesses and injuries that require long-term acute care. Provide
meaningful and occupation-based interventions to facilitate participation
in and independence with client-centered goals.

SOCIETY MEMBERSHIPS

American Occupational Therapy Association (AOTA)