A National Gateway to Self-Determination

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# Promoting Self-Determination for Adults: A Practice Guide

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# The National Gateway to Self-Determination

The National Gateway to Self-Determination (SD) is a consortium of University Centers for Excellence in Developmental Disabilities (Missouri, Kansas, Oregon, New York, Illinois) in partnership with a National Self-Determination Alliance (including self-advocates, families, and numerous national partners). The overall goal of this project is "***to establish a sustainable, evidence-based training system that enhances self-determination training programs that lead to quality of life outcomes for individuals with developmental disabilities throughout the lifespan."***

There are a number of important beliefs upon which this SD initiative is founded. They include:

- SD is best considered in the context of a ***social-ecological framework***
- Development of SD is a ***lifelong process***
- Scaling-up SD training activities must occur within an ***evidence-driven*** framework
- The development of SD is a means to obtaining an ***improved quality of life***
- People with developmental disabilities ***must be equal partners***

For more resources on self-determination, please visit the National Gateway to Self-Determination website: www.aucd.org/ngsd.

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## Preface

### Audience for the Practice Guide

This practice guide's primary intended audience involves practitioners working with adults having disabilities, who can apply and implement the evidence-based recommendations presented herein to teach skills related to self-determination and provide sufficient opportunities for utilization of these skills. The practices described in this guide can also be adopted by organizations that provide support to adults with disabilities. Additionally, the guide may point to future directions in research by highlighting concepts that currently have little to no empirical backing. For each recommendation we define the level of empirical evidence supporting it and the social validity associated with that recommendation.

### Scope and Methods for Building this Practice Guide

Development of this practice guide began with a search of the available empirical research documenting the development or impact of self-determination with adults who have been identified as having developmental disabilities. Search criteria were limited to peer-reviewed studies published between 1990 and 2009. This range of years is inclusive of empirical research that has been published since the emergence of the modern definition of self-determination. Articles included in the formulation of the recommendations of this practice guide also met the following criteria: (a) were reported as results of interventions (quantitative and/or qualitative designs), (b) included at least one participant with a disability, (c) included participants of ages 21 and older (eighteen and older was considered if the intervention was not school-based) and (d) measured one or more of the conditions/skills based on our organizational framework of self-determination as a dependent variable in empirical research

or as a research question in qualitative studies. Our search criteria consisted of the following keywords used in combination or exclusively (based on the dimensions and skills/conditions in Figure 1): *self-determination, adults, disabilities, goal setting, self-monitoring, self-instruction, self-evaluation, self-delivered reinforcement, self-recruited feedback, disability awareness, self-awareness, choice-making, decision-making, problem-solving, self-advocacy and leadership, social capital, community inclusion, community participation, independent living, and dignity of risk*. A number of electronic data-bases were accessed for these searches such as: The Educational Resources Information Center (ERIC), Education Abstracts, PsycINFO, Academic Search Premier, and Google Scholar.

A total of 27 peer-reviewed research articles met the inclusion criteria for further review. These articles resulted in four recommendations described in this practice guide in terms of their ability to enhance the promotion of self-determination. A number of studies were excluded from our review because they examined the effects of self-determination skills/conditions as an independent variable on another skill rather than on directly improving self-determination skills.

## Introduction

The major goal of this practice guide is to provide a summary of four evidence-based practices for developing and using self-determination for those who work directly with adults having intellectual and developmental disabilities (I/DD). A growing literature exists regarding self-determination, but only a modest percentage of this literature provides rigorous and empirical analysis, and the majority of such empirical analysis is focused on school-age populations. This practice guide focuses on what we know about building, supporting, and sustaining self-determination for adults who have developmental disabilities. While the guide is targeted to the families of individuals with I/DD and to support personnel, a secondary audience consists of researchers who are considering how to address current needs for documentation about self-determination.

This guide is intended as a companion to the Loman et al. (2010) practice guide, which focused on self-determination issues and strategies for children and adolescents with disabilities. Though self-determination is a universal concept that can be applied to all individuals, there are components that are unique to adults. The aforementioned practice guide for youth focused on school-based interventions. Rights and responsibilities differ considerably for individuals over the age of 18, as do social opportunities and mores. Self-determination for adults involves a variety of settings; with supports provided in the home, workplace, and the community. Goals regarding living accommodations, jobs and careers, and frequency and types of social activities are quite different for adults. The rights and responsibilities of adults also warrant a unique approach to providing self-determination

supports. Because of these differences, a unique body of literature has emerged that explores self-determination with the adult population and forms the content of this guide.

The intent of this guide is to provide those who work in various capacities in supporting adults having disabilities with an array of tools that have been empirically validated and are beneficial in improving the self-determination of adults. For purposes of this guide, we examined literature that focused on ages 21 and older.

**Adult Self-Determination**

The ability to make decisions that affect one's life is vital for all individuals, including those individuals with intellectual disabilities (Kennedy, 1996). For adults, this equates to a greater degree of independence, regardless of one's support needs in other areas. One does not need to be totally self-sufficient to be considered self-determined, but must have some input in the supports that are received. The acquisition of skills related to self-determination is vital for increasing any person's independence.

Self-determination is a concept that is fundamental to the shaping of many policies for providing residential and vocational supports to individuals with intellectual disabilities. Self-determination provides the conceptual foundation for policy, vision, and the operation of social systems in the field of developmental disabilities. As the developmental disabilities field has evolved from early assumptions about "handicap" and "disability", the central role of the individual has been captured and expressed by the construct of "self-determination" (see Appendix A for a full definition of self-determination).

We are better at describing the construct of self-determination than in delivering the practices for realizing self-determination. ***A need exists to link the vision and promise of self-***

***determination with both existing empirical evidence, and overt description of the practices that will help us better realize a society in which self-determination is an achievable goal for all citizens.*** The promotion of self-determination has become a recognized best practice in the support of individuals with intellectual and developmental disabilities. Self-determination offers a broad vision with strong personal implications. It is a construct with multiple facets and, as such, there will be no single practice or package of practices for achieving self-determination that applies to all people or all contexts. We offer in this practice guide: (a) a description of the way in which self-determination has been defined, (b) an organizational framework for linking practices that will enhance self-determination, and finally (c) a brief summary of the research literature supporting use of these practices.

**Understanding, Appreciating, and Actively Promoting Self-Determination**

Research has shown that the ability and opportunity of individuals with disabilities to shape their chosen outcomes has a positive impact on their future outcomes (Hadre & Reeve, 2003) and overall quality of life (Lachapelle et al., 2005; Wehmeyer & Schwartz, 1998). Such outcomes include: access to general education instructional settings (Agran, Blanchard, Wehmeyer, & Hughes, 2001), financial independence, independent living, and employment (Sowers & Powers, 1995; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). These articles assert that individuals with developmental disabilities who leave school as “self-determined young people” are more likely to: (a) be independent one year after graduation; (b) live somewhere other than where they lived in high school one year after graduation; (c) be employed for pay at higher wages one year after graduation; (d) be employed in a position that provides health care, sick leave, and vacation benefits three years after graduation; and (e) live

independently three years after graduation (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). Further, the acquisition of skills often related to self-determination has been shown to positively impact academic skills, study skills (Copeland & Hughes, 2002; Konrad et al., 2007), and possible reductions in high school drop-out rates (Zhang & Law, 2005).

Unfortunately, research also indicates that youth and adults with disabilities are less self-determined than their non-disabled peers due mainly to fewer opportunities to make choices and express preferences across their daily lives (Chambers et al., 2007). Additionally, numerous teachers who work with individuals having disabilities believe that the skills and knowledge related to promoting self-determination are often too complex for their students to learn (Agran & Wehmeyer, 2003) and, as a result, they fail to delineate goals in an individual's program specific to improving self-determination. Thoma, Pannozzo, Fritton, & Bartholomew (2008) found that, though many teachers could loosely define self-determination, identification of supportive skill sets varied from teacher to teacher. Further, some teachers could identify instructional strategies that addressed some skills, but they were unable to come up with methods to address others. Such evidence indicates that teachers need more direct instruction on (a) the importance of self-determination, (b) the strategies for establishing, honoring and promoting self determination, and (c) procedures for on-going assessment of impact.

Given that the promotion of self-determination has a strong influence on life-long outcomes for people with disabilities, it is important to translate the importance of work conducted to define the construct of self-determination into effective practices. In this practice guide we have used the organizational framework described in Appendix A to link practices that

have been empirically shown to enhance both discrete and overall self-determination for individuals with disabilities.

**Levels of Evidence**

Our aim in this practice guide is to provide an explicit and clear delineation of the quality and quantity of evidence that supports each recommendation. Studies were reviewed for content and quality of methodology. Content review forms included gathering information on (a) study design (e.g., single-subject multiple-baseline, group design pre/post, etc.), (b) independent variables, (c) measurement frequency of independent variables and dependent variables, (d) sample size, (e) sample selection procedures, (f) self-determination skill/condition addressed, and (g) results (e.g., statistical significance, effect size). To define the strength of supporting evidence, we have adapted a semi-structured hierarchy recommended by the Institute of Education Science (IES; Appendix C). This classification system helps determine whether the quality, quantity, and social validity of available evidence supporting a practice is "strong", "moderate", or "emerging". *Strong* refers to consistent and generalizeable evidence that an approach or practice causes improved performance in a dimension or condition of self-determination (see Table 1 and Appendix C). *Moderate* refers either to evidence from (a) studies that allow strong causal conclusions but which cannot be generalized with assurance to the target population because, for example, the findings have not been sufficiently replicated, or (b) studies that are generalizeable but have more causal ambiguity than that offered by experimental designs--for example, statistical models of correlational data or group comparison designs where equivalence of the groups at pretest is uncertain. *Emerging* refers to expert

opinion based on reasonable extrapolations from research and theory on other topics and/or evidence from studies that do not meet the standards for moderate or strong evidence.

In evaluating the level of evidence of social validity for a practice, it was judged to have S*trong* social validity if the empirical support for the practice included (a) several clear demonstrations that the reported interventions produced effects that met defined clinical needs, (b) measures of stakeholder reports of acceptability of procedures and feasibility were within the limits of available resources, (c) perceived effectiveness; and (d) follow-up measures demonstrating that typical intervention agents continued to implement procedures with fidelity after formal support was removed. A practice was considered to have *Moderate* social validity if empirical support for that practice included: (a) several clear demonstrations that the reported interventions produced effects that met defined clinical needs, and either b) measures of stakeholder reports of acceptability of procedures and feasibility were within available resources, along with their perceived effectiveness; OR (c) follow-up measures demonstrating that typical intervention agents continued to implement procedures with fidelity after formal support was removed. A practice that did not meet the standards for *Strong* or *Moderate* social validity was considered as having an *Emerging* level of social validity.

Using this scale to evaluate levels of evidence within the literature, This Practice Guide provides four recommendations for promoting self-determination for adults with disabilities (see Table 1).

Table 1. Recommendations and Corresponding Levels of Evidence

| *Recommendations* | | *Level of Evidence* | *Level of Social Validity* | *Number of empirical studies* |
|---|---|---|---|---|
| 1 | Use direct and explicit instructional strategies to teach component skills of self-determination, such as choice-making, problem solving, and self-advocacy/leadership skills. | Strong | Moderate | 12 |
| 2 | Use Person-Centered Planning Methods | Emerging | Emerging | 3 |
| 3 | Use structured programs designed with self-operated prompts to teach self-instruction skills. | Emerging | Moderate | 3 |
| 4 | Organize environments to provide opportunities for integration and self-direction | Moderate | Moderate | 9 |

In the following sections, we provide for each of the four recommendations, a definition of the practice, level of supporting evidence and social validity, a brief summary of support for the practice, how to implement the practice, and identified barriers or limitations of the practice.

## Recommendation #1: Use Direct and Explicit Instructional Strategies to Teach Component Skills of Self-Determination, Such as Choice-Making, Problem Solving, and Self-Advocacy/Leadership Skills.

Due to fewer opportunities to express preferences and make decisions affecting their daily lives, adults with disabilities are frequently viewed as being less self-determined than their non-disabled peers (Chambers et al., 2007). On the contrary, a significant body of empirical research has demonstrated that individuals with disabilities can learn to effectively engage in self-determination skills such as choice-making, problem solving, and self-advocacy. Further, they should be recognized as causal agents who are capable of making decisions that impact and control their lives (Bambara, 2004; Wood, Fowler, Uphold, & Test, 2005). The authors of this practice guide recommend that adults with disabilities be directly and explicitly taught self-determination skills, and also provided with the necessary opportunities, experiences, and supports needed to fully apply and utilize those skills. Direct and explicit teaching methods include such practices as: (a) modeling, (b) using various prompting techniques, and (c) providing multiple opportunities to practice and receive feedback on newly acquired skills.

**Level of Empirical Evidence: Strong**

We judge this recommendation as having a high level of supportive evidence based on a significant number of well-designed single-case studies clearly demonstrating a functional relation between the implementation of procedures for teaching components of self-determination and socially-significant outcomes for adults with disabilities.

**Level of Social Validity Evidence: Moderate**

The level of social validity demonstrated in the studies related to choice-making was judged to fit the criteria for moderate evidence. The rating of moderate was based on the inclusion of generalization and follow-up measures demonstrating that procedures continued to be implemented after formal interventions were removed as well as the socially important outcomes clearly demonstrated in the studies examined.

**Brief Summary of Supporting Evidence:**

**Choice-Making**. Choice-making has been the most highly emphasized component of self-determination in the large body of theoretical and empirical literature on the subject (Wehmeyer et al., 1998). *Choice- or decision-making* can be defined as the ability to recognize, weigh, and choose between different options based upon an understanding of the potential challenges and benefits associated with each of those options. Researchers have demonstrated that adults with severe developmental disabilities and limited verbal skills can learn to communicate preferences. For example, Nozaki and Mochizuki (1995) utilized a prompting and positive reinforcement procedure to train a 27-year-old woman living in a residential facility for individuals with severe disabilities to communicate choice preferences using objects representing various leisure and life-skills activities. As a result, choice-making increased within the training setting as well as in non-trained settings, with various activity partners. Hanley, Iwata, and Lindberg (1999) trained 4 adults living in a residential facility for individuals with developmental disabilities to choose between photographs of activities. Choice-making was followed by immediate access to selected activities and clear preferences emerged for all participants.

Additional studies have also shown that adults with developmental disabilities can learn to make choices and express preferences in community settings. Cooper and Browder (1998) used a most-to-least prompting strategy to teach three adults with severe disabilities to make choices between food items at various restaurants in their community. Browder, Cooper, and Lim (1998) utilized an errorless teaching procedure with constant time delay to teach older adults with disabilities to choose preferred leisure activities at a community recreational center for older adults. They found that durations of participation in preferred activities were longer in integrated settings with non-disabled older adults than in residential settings.

In addition to demonstrating that adults with disabilities can learn to express choices regarding everyday preferences, empirical evidence also indicates that the skills needed to make decisions with more far-reaching consequences can be directly and explicitly taught. Reid, Parsons, Green, and Browning (2001) used modeling and prompting to teach three adults with severe disabilities at a community job site to select preferred job-related materials and to choose between working with or without adaptive devices. When allowed more opportunities to make job-related choices following training, the level of assistance needed to complete job tasks decreased and completed tasks immediately increased substantially for all three adults. More recently, Dukes and McGuire (2009) provided sex education instruction to four adults with moderate intellectual disabilities that resulted in improved scores on an assessment developed to measure the ability of individuals with disabilities to make choices/decisions related to sexuality and sexual behavior.

**Problem Solving.** Problem solving is needed when engaging in tasks or in situations where the solution to a given problem is not easily discernable or attainable (Wehmeyer &

Schwartz, 1998). Research has shown that problem-solving skills of individuals with special needs can be enhanced through the use of direct and explicit teaching practices. Hughes (1992) used prompting, feedback, and praise to help four adults with severe intellectual disabilities learn to respond in both trained and untrained problem situations. The participating adults learned to state the problem and alternative solutions, and to choose the solution that would most effectively solve the problem in both training and novel problem situations occurring in the group home facility where the adults resided. Maintenance data collected 24 weeks after teaching sessions ended showed positive long-term gains. Bambara and Gomez (2001) used similar procedures to teach problem-solving skills to three individuals with disabilities who lived at home with family members. In addition to verbalizing problems and solutions, the participating adults in this study also learned to provide 'self-praise' when they identified effective solutions. Positive maintenance and generalization outcomes were also reported by the authors.

Devlin (2008) evaluated the effects of the Self-Determined Career Development Model (SDCDM) on the performance of job-related tasks by adults with moderate disabilities who were employed in competitive work settings. The SDCDM is a multi-component treatment package with a focus on problem solving at each step in the process. Using the program, individuals learn to state the problems to be solved and/or barriers that need to be removed when deciding on career goals, developing action plans, and assessing or adjusting goals and plans. In the 2008 study, Devlin found that following training on how to use the SDCDM, all participants were able to effectively engage in problem-solving and successfully achieve their self-chosen work-related goals.

**Self-Advocacy/Leadership.** The ability to identify and express one's wants and needs and to recruit support from others when necessary is a legitimate expectation for success in adulthood. Self-advocacy has been shown to be a key to successful outcomes related to secondary education and employment (Gerber & Price, 2003). Research has also demonstrated that the self-advocacy/leadership skills of adults with disabilities can be improved through direct and explicit teaching procedures. For example, Balcazar, Fawcett, and Seekins (1991) used a multi-component modeling, role-play, corrective feedback and praise procedure to teach university students with disabilities to recruit help from others in attaining personal goals. Teaching was based on a written training manual, and participants were allowed to move from one chapter to the next as they correctly completed all six of the role-play scenarios for each lesson. Results demonstrated that all participants showed significant improvement in recruiting skills both in simulated scenarios and in real-life generalization contexts.

Faw, Davis, and Peck (1996) used direct instruction, modeling, practice and feedback procedures to teach four young adults with mild developmental disabilities to evaluate potential group home settings. The participating adults learned to successfully: (a) identify preferences, (b) obtain information about each of the group homes, (c) select suitable home environments based on personal preferences, and (d) communicate those preferences to their social workers. Additionally, Bollman and Davis (2009) utilized direct instruction, practice role-plays, corrective feedback, and praise to teach two adult women with mild intellectual disabilities to identify, react to, and report inappropriate interactions with residential facility staff members. Results were shown to successfully generalize outside of the training setting for both participants.

In summary, for an individual to exhibit self-determined behavior, he or she must be able to recognize and choose between available options, develop a plan of action based on the resources available, determine who or what is necessary to carry out that plan, and elicit support when needed (Illinois Planning Council on Developmental Disabilities, 1992). There is a large body of single-case research demonstrating that adults with special needs can, when provided with the opportunity, act as causal agents and make choices that affect the course of their lives. However, in order to facilitate the expression of self-determination, direct and explicit instruction of self-determination skills is often required.

**How to Implement**

- Prior to explicitly teaching self-determination components, it is important to assess an individual's current skill set. It may first be necessary to teach prerequisite skills in order for the individual to learn to associate specific responses with the consequence(s) for those actions, or for individuals with limited verbal skills to learn alternative communicative responses.
- Explicitly teach the skills of identifying, evaluating, and selecting options, along with how to develop a plan of action.
- Present all tasks both in formal teaching situations and in more naturalistic contexts to enhance generalization.
- Build opportunities into daily routines so that individuals have multiple opportunities to practicing self-determination skills throughout the day..

- Teach strategies in how to make choices, problem solve, and recruit help in academic, leisure, and social contexts.
- Begin by providing a limited number of options in selected domains, then increase the number of options and domains in which choices are provided as skills improve.
- Clearly communicate the limits of choice-making (those situations/tasks which are non-negotiable).

**Recommendation #2: Use Person-Centered Planning Methods to Empower the Construction of Goals, Choice-Making, and Self-Advocacy.**

**Defined**

Person-centered planning (PCP) is a term describing a collection of similar approaches used to assist individuals in planning their futures. The goal of these approaches is to aid individuals in developing meaningful life goals based on their strengths and talents, utilizing individual, natural, and creative supports and services (See Mount, 2000). There are a number of packages that have been developed to help individuals and teams to create person-centered plans. Some of those discussed in the literature include Personal Futures Planning (PFP; Mount, 1987), Making Action Plans (MAPs; Forest & Lusthaus, 1989), Essential Lifestyle Planning (ELP; Smull & Harrison, 1992), and Planning Alternative Tomorrows with Hope (PATH; O'Brien & Forest 1995). The various person-centered approaches have been summarized as sharing a set of common characteristics by: (a) viewing the individual as a person first, rather than as a diagnosis or disability; (b) using everyday language, pictures, and symbols, rather than professional jargon; (c) planning that is centered around each person's unique strengths, interests, and capacities within the context of living in the community; and (d) giving strength

to the voices of the individual and those who know him or her most intimately in accounting for such tasks as documenting history, evaluating her or his present conditions in terms of valued experiences, and defining desirable changes in his or her life (Kincaid, 2005).

In analyzing the literature on the use of person-centered planning methods for adults, three peer-reviewed studies (Heller, Miller, Hseih, and Sterns , 2000; Combes, Gillian, & Buchan 2004; Robertson et al., 2007) were identified that empirically assessed the impact of person-centered planning. These 3 studies suggest that person-centered planning played a significant role in supporting individuals with intellectual disabilities in (a) setting goals, (b) making choices, and (c) advocating for themselves. Combes, Gillian, and Buchan(2004) presented the use of Q-sort methodology (i.e., statistical analysis that enables the interpretation of ranked choices selected by individuals and their support circles) to demonstrate similarities and individual differences for goal planning. Their work presented the use of Q-sorts over time as a means to identify persons' values and demonstrate the subjective change in their values that occur through person-centered planning. Results from the study by Combes et al. also suggested that circles of supports can share the same values as individuals with intellectual disabilities. Robertson et al. (2007), in a 2-year study of 93 adults with intellectual disabilities, found that person-centered planning development with organizations resulted in the following outcomes for adults with disabilities: (a) increased social networks, (b) increased community involvement, (c) increased scheduled day activities, (d) improved contact with friends, and (d) improved choice-making. Heller and colleagues (2000) conducted a comparison study with older adults which suggested that individuals who participated in person-centered planning trainings improved in their overall knowledge of : (a) choice-making, (b) work and retirement,

(c) health and wellness, (d) living arrangements, and (e) leisure activities. Furthermore, they showed that the ability to make daily choices by adults with disabilities improved due to participation in later life person-centered planning.

**Level of Evidence: Emerging**

We judge this recommendation as demonstrating an *emerging* level of evidence based on studies evaluating the effectiveness of person-centered planning in facilitating individuals' skills related to self-determination. There were three published studies examining outcomes for individuals who receive person-centered planning, and it is difficult for researchers to differentiate degrees of person-centeredness of the planning methods used.

**Level of Social Validity Evidence: Emerging**

The level of social validity demonstrated in the studies related to person-centered planning was judged to fit the criteria for *emerging e*vidence. This rating was based on the degree to which socially important outcomes were evident in the studies examined, as well as the inclusion of follow-up measures demonstrating that procedures continued to be implemented following intervention.

**Brief Summary of Support for the Practice**

A considerable amount has been written about person-centered planning in the last two decades. Much of the published literature discusses theoretical advantages and qualitative changes in a person's outcomes based on supports stemming from this philosophy. To date, however, there are only a handful of studies that have quantitatively examined the outcomes of the use of person-centered planning techniques. Further, though some versions of person

centered planning have existed since 1980, there has been little work on evaluating specific curricula.

While there have been some empirical studies that have involved the use of person-centered planning, there are few that have examined change related to self-determination. Many of the studies utilized surveys and examined changes in quality of life as perceived by the individual and those who are familiar with him or her.

Several studies examined outcomes that are aligned with increases in qualities related to self-determination. For example, Robertson, Emerson, Hatton, Elliott, McIntosh, and Swift, et al. (2007) looked at variables such as choice-making, access to social networks and involvement in community-based activities, and found increases across these domains resulting from the utilization of person-centered planning.  Dumas, De La Garza, Seay, and Becker (2002), examined changes in the perception of self-efficacy as a product of person-centered planning with a sample of thirteen individuals having disabilities. They found qualitative changes in reported self-efficacy and also that sometimes small requests were most meaningful to the individual. However, the study also noted that case coordinators and facilitators of the person-centered planning process can actually impede the self-efficacy of the individual if not properly prepared for their roles.

Holburn, Jacobson, Schwartz, Flory, and Vietze (2004) noted that the use of person-centered planning in conjunction with positive behavior support planning led to better outcomes for participants. Everson and Reid (1999) discussed the importance of follow-up after initial planning meetings to ensure positive outcomes.  Finally, both Hagner,, Helm, & Butterworth (1996) and Heller, Factor, Sterns, & Sutton (1996) noted that fidelity of

implementation is vital for effective person-centered planning. Thus, the available evidence on person-centered planning clearly establishes it as a viable method for enhancing self-determination among adult populations with developmental disabilities.

**How to Implement**

The methodology recommended by each of the person-centered planning curricula (see reviewed) follows a similar course.  That is, the individual first forms a team of supporters including key members of school and home contexts. This often includes an individual who can act as an advocate for the target individual. This person should have no vested interest in the outcomes of the planning sessions beyond those of the individual. Other team members may include family, case manager(s), personal assistants, advocates, and vocational personnel as applicable.

The following guidelines are provided for use in the effective teaching of person-centered planning strategies and processes:

- Over the course of two or more meetings, a plan is created that encapsulates the individual’s preferences and goals regarding living arrangements, vocational/school goals, social interests and personal fulfillment.
- A quality person-centered plan includes a detailed action plan for achieving or approximating these goals as well as tracking discussion regarding the potential roadblocks as perceived by team members.
- The first meeting should be spent allowing the target individual and other team members an opportunity to freely describe goals and objectives.

- In most person-centered planning programs, a forum is established in which team members can voice their concerns and discuss potential roadblocks in the action plan. These can be discussed with the team while allowing the individual's opinion to be the primary voice in the discussion.
- Follow up meetings are used to establish a course of action to work towards these goals.
- Teams should establish short-term goals and objectives and reevaluate them based on that individual's progress along the stated objective.
- Each objective will look different, when tailored to the individual's needs, desires, and abilities; as well as the resources available to meet these demands.

**Recommendation #3: Use Structured Programs Designed with Self-Operated Prompts to Teach Self-Instruction Skills.**

**Defined: An Instructional System That Teaches Specific Skills (e.g., Performance of Chained Tasks) Through the use of Audiovisual Prompts That Can Easily be Manipulated by the Learner.**

There has been a strong interest in the development of strategies to help people with developmental disabilities acquire, maintain, and generalize skills with minimal supervision (Ackerman & Shapiro, 1984; Anderson, Sherman, Sheldon, & McAdam, 1997; Connis, 1979; Lancioni & Oliva, 1988; Simmons & Flexer, 1992; Wacker & Berg, 1983, 1984). Lancioni and O'Reilly (2001) identified five strategies of self-management of instructional cues which included the use of: (a) picture cues presented on sets of cards, (b) picture cues stored in computer-aided systems, (c) object cues attached to cards, (d) verbal cues stored in audio recording devices, and (e) self-verbalizations. Audiovisual prompts (including computer-aided

systems) incorporate features of all 5 of these strategies to aide in the acquisition, maintenance, and generalization of multistep tasks. In addition, the use of audiovisual prompts has "been used to enable the performance of sequences of familiar activities and simple tasks scheduled in the persons' environment" (Lancioni & Reilly, 2001, p. 47). An audiovisual prompting system is a practical way of prompting multistep tasks while: (a) avoiding possible problems with the handling of cards, (b) regulating opportunities for reinforcement within the instructional context, and (c) dealing with losses of concentration and breaks in an individual's performance.

**Level of Evidence: Emerging**

We judge this recommendation as demonstrating *emerging* evidence based on studies evaluating the effectiveness of assistive devices and self-instruction in facilitating individuals' skills related to self-determination. Given the advances in technology and availability of assistive devices in the 21st century, the use of assistive devices and self-instruction show much promise for improving the self-determination of adults with disabilities.

**Level of Social Validity Evidence: Moderate**

The level of social validity demonstrated in the studies related to the use of structured programs with self-operated prompts was judged to fit the criteria for *emerging* evidence. The rating of moderate was based on the degree to which socially important outcomes were demonstrated in the studies examined, as well as the inclusion of follow-up measures demonstrating that procedures continued to be implemented following intervention.

**Brief Summary of Support for Practice**

A review of the literature regarding practices for adults with disabilities yielded 3 peer-reviewed studies supporting effective strategies for using self-instruction. Feldman and Case (1999) presented the efficacy of a self-instructional audiovisual child-care manual that showing that self-instruction was effective with 9 of 10 parents with intellectual disabilities on 11 of 12 skills that were taught. They used illustrated picture books and checklists for child-care skills paired with audiotapes that directed the listener to look at a picture. The dialogue on the audiotape read text related to the individual skill being taught. Devine, Malley, Sheldon, Dattilo, and Gast (1997) used calendar and telephone prompts as a means to help individuals with intellectual disabilities initiate community activities. The researchers conducted the study with six individuals living in a residential setting. They found that the participants increased their capacity to initiate activities when both prompts were used.

Lancioni, O'Reilly, and Oliva (2001) found that adults with disabilities could use a self-operated verbal instruction system (i.e., audio cassettes containing prerecorded sequences of task instructions) to learn relevant tasks (e.g., putting seeds and small plants in pots, assembling a lamp, wall decoration, table decoration, or special container). The participants were able to push an operation key on the tape player to receive instructions related to the desired tasks. Instructions recorded on the audiotapes were "clustered" in two or more successive task steps to: (a) reduce instructional occasions after task acquisition and (b) improve the individual's independence and possibly self-confidence.

**How to Implement**

The methods used in the studies defining the use of structured programs with self-operated prompts suggested a series of overlapping steps to teaching specific self-instructional skills. The steps below are based on the ones used within those studies:

- Identify the skills/tasks that the individual wants to learn (using person-centered planning methods as discussed earlier in this practice guide).
- Outline the steps required to complete the task.
- Develop a step-by-step procedure that includes simple pictures or photos and text paired with audio instructions (the use of video with simple examples may also be used).
- Ensure that devices used (tape recorder, mp3 player, etc.) have the capability for users to start, stop, and rewind directions.
- Use simple sentences of three to six words (e.g., take the bucket with dirt, take the bottle with water, empty the bottle in the bucket; Lancioni et al, 2001).
- Intersperse instructions with encouragement using praise messages.
- When designing an instructional system (depending on the individual's skill level) ensure that the system stops or pauses for each 1-2 verbal instructions emitted by the system (e.g., take the bucket with the dirt) to enable the completion of steps. It may be advisable to build in a system where a button must be pressed to move on to the next step.

- When first starting a new instructional system, introduce the task/skill with four to six practice sessions where verbal and physical prompts are available to acquaint individuals with the use of the system and the recommended responses.

**Recommendation #4: Organize Environments to Provide Opportunities for Integration and Self-Direction**

The self-determined individual must have opportunities to utilize skills related to self-determination and must be allowed more independent access to her/his community. This includes teaching skills to those who support the individual in order to allow these opportunities.

**Level of Evidence: Moderate**

We judge this recommendation as demonstrating a *moderate* level of evidence based on studies evaluating the methods for increasing integration and resulting increases in self-determination. There were nine published studies demonstrating supports that increase opportunities for self-determination for adults.

**Level of Social Validity Evidence: Moderate**

The level of social validity demonstrated in the studies related to opportunities for integration were judged to fit the criteria for *moderate e*vidence. This rating was based on feedback provided by participants, as documented in the studies, as well as the degree to which socially important outcomes were demonstrated in the studies examined. There was also inclusion of follow-up measures in several studies, demonstrating that procedures continued to be implemented following intervention.

**Creating Opportunities for Community Integration**

Vine & Hamilton (2005) examined several variables, including age, length of institutionalization, and daily living skills with 37 individuals having intellectual disabilities. Daily living skills were correlated positively with community integration though it cannot be surmised from the data that community integration caused increases in daily living skills, only that these variables were highly correlated. Wehmeyer and Bolding (1999) examined self-determination in both home and vocational settings for individuals with intellectual disabilities. They found that the participants experienced varying degrees of self-determination, autonomy, and satisfaction across these settings, noting the potential for greater opportunities where the individual had demonstrated competence in another setting. In a follow-up study, Wehmeyer and Bolding (2001) found that participants with developmental disabilities showed great increases in self-determination, autonomous functioning, and life choices when they moved from a more restrictive to a less restrictive work or living environment. Lastly, Stancliffe, Abery, and Smith (2000) examined the levels of self-determination of 74 adults in comparison with levels of personal control that they experienced. This study found a strong correlation between placement in less restrictive settings and the corresponding self-determination of the individual.

While deinstitutionalization has lead to an increased *physical* presence in the community, actual involvement and participation require more than a change of residence. Thorn, Pittman, Myers, and Slaughter (2009) reported a study examining changes in participation with staff training and education in the importance of this aspect of resident life. Their sample included 556 individuals with disabilities (all but four of whom were over 21 years

of age). The training consisted of three stages. In the first stage, staff members were trained to increase exposure in the community. In the second phase, they were taught the importance of integration and functional interaction. The third phase linked goals established in the individual support plan to integration activities and helped staff to create and maintain objectives that targeted activities to facilitate integration. The researchers found that this training tripled the frequency of integrating activities. Further, the frequency appeared to remain fairly consistent in the maintenance phase following training.

Smalley, Certo, & Goetz (1997) also reported a study examining the effects of caregiver training on community integration activities. They utilized a multiple baseline design with five "behavioral aides" (direct support personnel). The intervention consisted of several components: a) completion of a functional assessment interview regarding the predictability of the person's schedule, variety in the schedule, their ability to make choices, and the presence of non-paid individuals in the person's life, b) training in and completion of Valued Outcomes Information System (VOIS) data outlining daily activities, and c) discussion of the importance of an enriched environment. The researchers saw increases in the number of valued, socially enriched as well as physically enriched activities. They also showed ongoing maintenance of these activities following the intervention.

**Network of Personal Relationships**

Numerous studies have used the existence and maintenance of personal relationships as a targeted skill set. Milner and Kelly (2009) described the experiences of 28 individuals with disabilities entering the community in supervised settings and their reports of feeling like outsiders who are there for a short period of time. The authors advocate for a more sustained

presence in which the person is expected to be a contributing member. Participants in the study noted the need for a feeling of reciprocity in their interactions and involvements.

It is important for supporting personnel to provide opportunities for social networking with others who have similar interests – not just similar support needs. Per the self-determination and person-centered planning literature, this doesn't just involve accessing the community. Meaningful integration into activities and social situations that are highly valued and emotionally fulfilling is a necessary prerequisite for achieving this important goal. In a study of 97 individuals with learning disabilities in post-secondary education settings (DaDeppo, 2009), social integration was found to be more critical than was academic integration to later success in college. While grade point average and entrance exam scores were more predictive of the general study population's success, these social factors weighed more heavily for those having learning disabilities.

**Community-Based Instruction**

Several studies have examined the use of instruction in the community as a means to develop increased participation and involvement in community settings. Nisbet, Clark, and Covert (1991) point out that though social skill development is important, aspects of the community and social factors play an equally important role in successful integration, implying that there is a need to practice skills in the settings in which they will be employed.

In another study (O'Reilly, Lancioni, & Kierans, 2000), researchers taught a generic set of rules for social interactions to individuals with intellectual disabilities. They utilized a multiple baseline design with three participants. These participants were taught how to discriminate salient social stimuli, change behaviors based on what is appropriate for the situation, perform

the interaction, and evaluate their own outcomes. In this case, the activity was interaction with bar staff and ordering drinks. All participants showed great improvement following the intervention.

Pawson, Raghavan, and Small (2005) developed a Social Integration Interview Schedule (SIIS) to aid in the social integration of six adults with intellectual disabilities. Many of the elements present in this system are similar to elements in person-centered planning in that individuals who are valued by the person are identified and placed in a visual representation in their proximity to the person (the closest being the most valued relationships). This particular system utilized laminated pictures of the people of interest, which were fastened to a board by the individual. The goal of this system is to aid in the planning for social networking and associated activities according to the person's preference(s).

**How to Implement**

- Determine the least-restrictive environment that allows for the health and safety of the individual. This should be determined independently for residential, vocational, and other settings.
- Placements are based on interests and personal preference rather than disability or need type (e.g. a person does not reside at a house because he/she is with others who have the same diagnoses).
- Structured opportunities are provided for access to areas of interest. Decisions are made based on the values of the individual.
- Allow and encourage direct interaction with other individuals in the community – not via staff proxy.

- Staff should be trained in self-determination awareness. They should be familiar with the person's interests and goals (as noted in person-centered planning).
- Individuals are given opportunities to practice social skills in community settings in which they will be utilized.
- Individuals become regularly attending and contributing members of groups that are formed around areas of interest.
- Utilize a system to track preferred interests and the frequency and duration of outings that are aligned with these interests.

**Conclusion**

In conclusion, the purpose of this practice guide is to provide a summary of the existing empirical evidence base related to practices for enhancing, supporting and sustaining self-determination among adults with disabilities. We have made four recommendations herein based on that evidence. We reemphasize that we have defined self-determination as a multi-dimensional construct comprised of a number of component skills or conditions (see Figure 1). As shown in our presentation of practices within the dimensions and conditions of self-determination (Table 3), there was no one practice reviewed that addressed all three dimensions (*Causal Agency, Proxy Agency,* and *Environmental Opportunities to Act*) of self-determination. It is our overall recommendation that our four individual recommendations be used concurrently or in combination to ensure the effective promotion of self-determination for adults with disabilities.

First we recommend that persons working to support adults with disabilities use direct and explicit instructional strategies to teach component skills that promote and enhance self-

determination, such as choice-making, problem-solving, and self-advocacy and leadership skills. Our next recommendation is to use person-centered planning methods to aid adults with disabilities in: (a) developing meaningful goals, and (b) utilizing self-advocacy skills to ensure access to available services and resources. Next we recommend the emerging practice of utilizing structured programs designed with self-operated prompts (e.g. audiovisual prompts that can be directly manipulated by the learner) to teach self-instruction and self-management skills. Finally, we recommend that environments be organized to provide ample opportunities for adults with disabilities to access the community independently and to fully utilize skills related to self-determination.

Although there is a growing body of research demonstrating the efficacy of various practices to develop and support self-determination among adults with disabilities, there are several dimensions that have been discussed in the professional literature regarding adult self-determination that have no corresponding evidence base (e.g. dignity of risk). Much of this dearth may be due to challenges associated with evaluating and measuring these constructs. Other such areas will certainly emerge, however, as the definition of self-determination evolves and as researchers continue to find new ways to approach this multi-dimensional construct as it relates to adults. Our current list of recommendations reflects the empirical evidence that presently exists to support practices for promoting self-determination for adults with disabilities. It is our hope that this list will be expanded and refined as related research in this area continues to develop.

Table 2. Presentation of Practices within the Dimensions and Conditions of Self-Determination

| | **Self-Determination** | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **Causal Agency/ Independence** | | | | | | | | **Proxy Agency/ Interdependence** | | **Environmental opportunities to act** | | |
| | **Self-management** | | | | | | | | | | | | |
| **Practices** | **Goal-Setting** | **Self-monitoring** | **Self-instruction** | **Self-evaluation** | **Self-reinforcement** | **Self-Feedback** | **Choice/ decision-making** | **Problem-solving** | **Self-advocacy/ Leadership** | **Social Capital** | **Social Inclusion** | **Enriched Environment** | **Dignity of Risk** |
| **Direct and Explicit Instruction** | X | X | X | X | X | X | X | X | X | | | | |
| **Person-centered planning methods** | X | | | | | | X | | X | X | X | X | X |
| **Self-operated prompts to teach self-instruction skills** | X | X | X | X | X | X | | | | | | | |
| **Opportunities for integration and self-direction** | | | | | | | | | | X | X | X | X |

## Appendix A

### Self-Determination Defined

Self-determination is a difficult concept to define precisely as it is complex and has multiple dimensions which have been described in different ways (Field, Martin, Miller, Ward, & Wehmeyer, 1998). Field et al. included a number of attributes related to self-determination, such as *awareness of personal preferences, interests and strengths, differentiation of wants and needs, choice-making based on these interests, preferences, wants and needs, problem-solving, self-evaluation of decisions based upon prior experience, self-regulation, communication and negotiation ability, goal-setting, and other skills related to goal derivation, modification, and attainment*. Martin and Huber Marshall (1995) include *self-awareness, self-efficacy, self-advocacy, decision making, independent performance, self-evaluation, and adjustment* as major constructs attributed to self-determination.

The dimensions underlying self-determination have been discussed in the literature since the concept of self-determination emerged in the 1960s. In 1972 for example, Benget Nirje applied the idea of self-determination to disability supports, with an emphasis on respect for the choices and aspirations of persons with disabilities. Subsequent articles focused on the choice components of self-determination, goal-setting and goal-attainment. The philosophy underlying self-determination also builds upon Nirje's (1972) normalization principle, along with Deci and Ryan's (1985) discussion of causal agency and the ability to take a self-directing role in decision making. Wehmeyer has expanded upon this important notion in a series of articles published in the last decade.

Other writings, while acknowledging the need for individuals to be a central part of making choices for themselves, have noted that choice making must be tied to the attainment of goals that are determined by individuals, based on their prior experience and evaluation of their needs and wants. Ward (1998) discussed the need for individuals to envision their own goals. Others have expressed the concern for individuals to perceive the need to adjust these goals and to do so as needed (Wolman, Campeau, DuBois, Mithaug, and Stolarski (1994).

For purposes of this practice guide, we approach self-determination within a social-ecological framework in which self-determination is seen as a psychological construct that refers to self- (vs. other-) caused action—to people acting volitionally, based on their own will. Volition refers to the capability of exercising conscious choice, decision, and intention. This theoretical approach draws on the work of the Gateway to Self-Determination Project (Wehmeyer et al., 2011). People who are self-determined serve as the primary causal agents in their lives; they cause or make things happen in their lives. They accomplish this outcome through self-caused action (causal agency) that has a clearly specified goal or purpose or through the actions of others taken on one's own behalf, referred to as proxy agency. Core assumptions associated with this approach to self-determination are:

- All individuals have the ability to be self-determined
- All individuals should be afforded the opportunities to practice self-determination
- Self-determination is a multidimensional construct
- Promoting self-determination for any person will require the unique combination or clustering of practices that meet the specific needs of that person. Delivering on the

promise of self-determination will seldom involve one practice, and will typically require individualized application of multiple practices.

- Self determination requires the teaching of skills as well as opportunities for the individual to practice these skills within natural environments and key social-personal contexts.

Within this social-ecological framework, activities to promote self-determination (e.g., interventions) might focus on building a person's capacity to perform actions leading to greater self-determination skills (e.g. problem solving, decision, making, goal setting, self-advocacy, etc.), focus on modifying the context or the environment in some way to better enable a person to make things happen in their own lives, or to provide necessary supports (e.g., technology) that enhance self-determination.

The Developmental Disabilities Act of 2000 defined "self-determination activities" as "activities that result in individuals with developmental disabilities, with appropriate assistance, having: (a) the ability and opportunity to communicate and make personal decisions; (b) the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individual receives; (c) the authority to control resources to obtain needed services, supports and other assistance; (d) opportunities to participate in, and contribute to, their communities; and (e) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities" (P.L. 106-402, section 102).

## Appendix B

**Organizational Framework for this Practice Guide on Self-Determination**

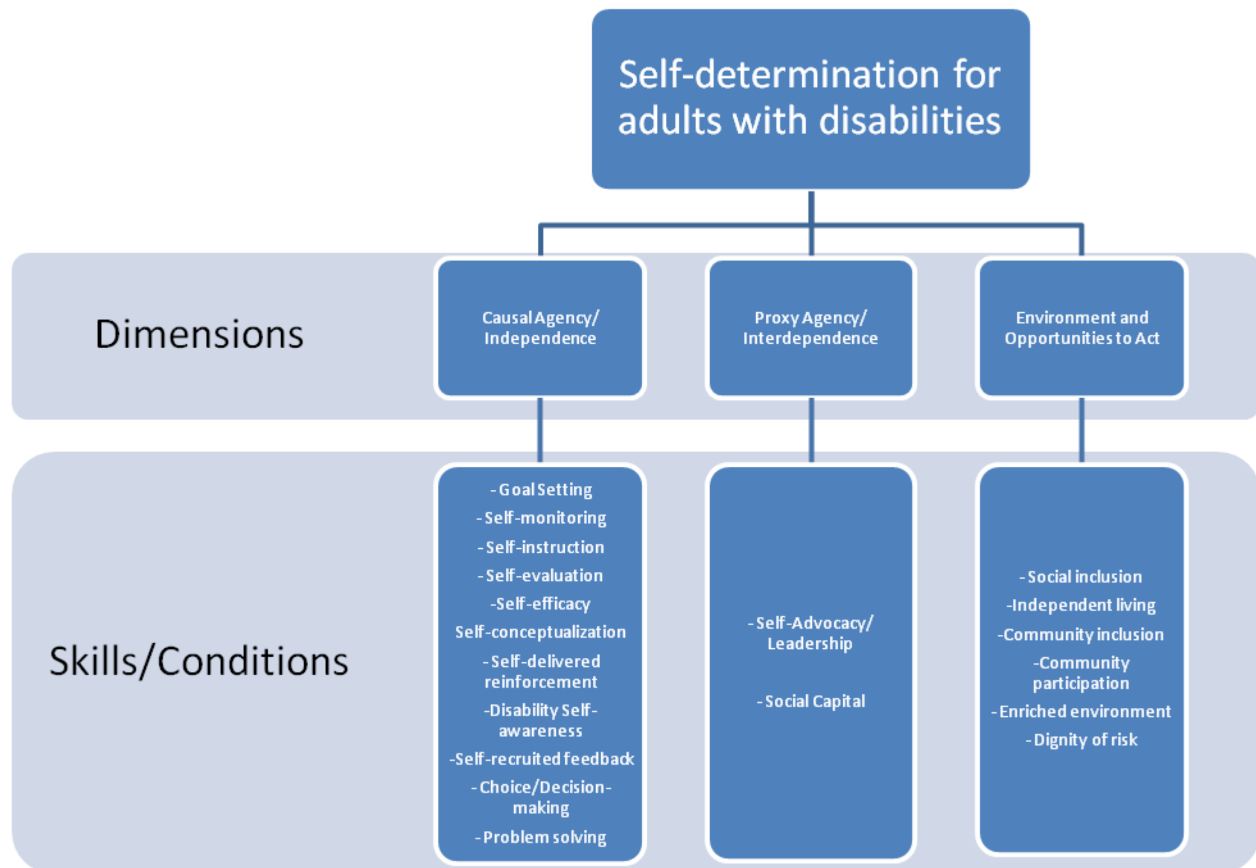
There are several sources that provide the theoretical underpinning(s) for the framework presented in this practice guide. As shown in Figure 1 and described in Wehmeyer et al. (2011), this framework provides a basis for the organization of practices that enhance adult self-determination as illustrated in this practice guide.

In addition, Walker et al. (2011) provide a summative conceptualization of self-determination, drawing from three primary theoretical frameworks : (a) functional theory of self-determination (Wehmeyer, 2003), (b) self-determined learning theory (Mithaug, 2003); and (c) an ecological theory of self-determination (Abery & Stancliffe, 2003). The socio-ecological model by Walker et al., (2011) emphasizes the promotion of one's "causal agency" (the individual's control of events) as well as "proxy agency" (provision of supports and assistance allowing the individual to control events) and finally "opportunities to act upon the environment." Readers desiring more detail on the socio-ecological model and the other cited models of self-determination are encouraged to read Walker et al, in (2011), Wehmeyer (2003) and Wehmeyer et al. (2011).

There are three core dimensions that comprise this organizational framework. Each of the interventions/practices can be related to one of these core dimensions: (a) Causal agency/Independence, (b) Proxy Agency/Interdependence, and (c) Environmental Opportunities to Act. These dimensions reflect the personal, social, and contextual dimensions through which individuals interact with the world around them. Within each of these dimensions, specific skills/conditions operate to enhance self-determination. Figure 1 displays

the dimensions and associated skills/conditions that empower individuals to act as causal agents on their behalf. A description of each dimension and definitions of these skills/conditions are discussed in the next section.

Figure 1. Organizational Framework of Adult Self-determination Dimensions and Skills/Conditions




**Dimension #1: Causal Agency/Independence**

Causal agency refers to the ability of the individual to act as the primary or central agent in making decisions regarding goals and specific action plans to reach these goals. The construct of "causal agent" emphasizes the inherent ability of all people to participate in achieving self-determination. That said, the cluster of contextual conditions and personal

strengths that persons bring to the situation will shape how they exercise available self-determination options. Skills that support causal agency/independence include (a) *self-management*, (b) *choice/decision-making*, and (c) *problem-solving*.

*Self-management* refers to the specific strategies a person uses to control and regulate their own behavior (Brooks, Todd, Tofflemeyer, & Horner, 2003). Self-management is a process by which the person who performs a maladaptive form of behavior uses self-regulation strategies to increase targeted desirable behaviors (Todd, Horner, & Sugai, 1999). Self-management involves multiple skills such as: recognizing, monitoring and regulating incoming stimuli, organizing these stimuli, and integrating them into current and future planning efforts. Specific sub-skills associated with effective self-management include: (a) goal-setting: (short and long-term planning to achieve identified accomplishments) (Zimmerman, Bandura, & Martinez-Pons, 1992); b) self-monitoring: (recording events and actions associated with one's own behavior) (Kafner, 1970); (c) self-instruction: (the self-delivery of prompts or comments that set the occasion for performing targeted behaviors) (Mithaug, Mithaug, Agran, Martin, & Wehmeyer, 2007);(d) self-evaluation: (judging the quality of one's performance against a defined criterion) (King-Sears, 2006); (e) self-efficacy: the belief that one can reach self-ascribed goals; (f) self-recruitment of reinforcement: (the increase in responding as a function of contingent self-delivery of a consequence) (Hughes, 1992; Mank & Horner, 1987); (g) self-awareness: an understanding of the resources required and the unique configuration of one's environment based on personal attributes (not just ability or disability) and (h) self-recruited feedback: the use of both self-evaluation and self-reinforcement: (recruitment of contingent feedback from the external environment) (Storey, 2007).

*Choice/Decision-making* and *problem-solving* are other skills underlying the dimension of *Causal Agency/Independence*. When faced with a number of divergent options, *choice/decision-making* involves recognizing and weighing decisions based upon an understanding of potential challenges, needs, and benefits. *Problem-solving* involves the recognition of potential barriers (short- and long-term) and the development of plans to circumvent or overcome them. The main difference between *Choice/Decision-making* and *Problem-solving* is that no direct or obvious solutions are apparent in Problem-solving. Thus, problem-solving tasks of necessity may be broken down into small instructional steps.

**Dimension #2: Proxy Agency/Interdependence**

*Proxy Agency/Interdependence* is the opportunity for an individual to act as a cooperative agent in a reciprocal relationship(s) with others. This dimension differs from *Causal Agency/Independence* in that an individual collaborates and works cooperatively with others (e.g. advocates) in certain situations or settings. The essential skills within the *Proxy Agency* dimension include *self-advocacy* and *social capital. Self-advocacy/leadership* is the expression of preferences and needs to elicit desired support from others (e.g., allowing support, defining parameters of support, etc.). *Social Capital* involves important social relationships based on trust and that benefit the individual while recognizing that individuals have the opportunity to impact others lives, through both social and tangible means.

The concept of social capital (Bourdieu, 1986; Coleman, 1988; Schalock et al., 2008) is closely related to both the dimensions of *Proxy Agency* and *Environmental Opportunities to Act.* Social capital relates to the resources available within communities as a function of networks of mutual support, reciprocity, and obligation (Franke, 2005), as well as specific processes that

occur among people and organizations working collaboratively that lead to accomplishing a goal of mutual shared benefit (Putnam, 1993). In these ways, the idea of social capital is directly tied to the access that an individual has to an enriched social environment and, therefore, the ability to act as an influential agent on others in that environment. This dimension of self-determination is particularly vital for adults, as an emphasis is placed on the individual to build and maintain essential social networks. While schools provide much of the scaffolding in this area for adolescents, adults with developmental disabilities have more of an array of social avenues in which to maneuver – (e.g. in vocational settings, continued education settings, community settings, and residential settings). These contexts provide powerful opportunities for both causal and proxy agency, but with more expectations placed upon the individual to seek them out and maintain them over time.

**Dimension #3: Environmental Opportunities to Act**

This dimension considers the access that individuals have available to them in order to recruit skills and supports that empower them to respond to the world around them. Environmental opportunities are much different for adults than they are for adolescents. In adulthood, expectations and opportunities are aligned with the individual's community. For individuals with disabilities, this doesn't just include community activities that are specialized in nature; but also groups, organizations, and locales that cater to any and all adults. *Community inclusion and community interaction* refer to the normative opportunities an individual has to participate and engage in activities available to everyone else. For adults with disabilities, the likelihood of social inclusion needs to be developed. This doesn't merely involve planned outings in the community facilitated by a support staff, but rather interactions with those who

are not paid support providers as well as independent outings when possible. An *enriched environment* refers to exposure to a range of opportunities that encourage a plethora of options for an individual (as opposed to a prescribed range of opportunities outlined by support staff or housemates).

*Dignity of risk* suggests that individuals must have the opportunity to balance choices that are in their own interest but which may also include risk to their lifestyle(s), health and/or safety. There are potential behaviors that adults with developmental disabilities engage in that may carry some degree of risk. Self-determination subscribes to the philosophy that individuals must be provided the dignity to make these choices, but with a clear understanding of the possible harmful consequences of one's actions. Having said this, it is the responsibility of advocates, caregivers, and professionals to assist individuals with developmental disabilities in coping effectively with the possible consequences of such actions.

## Appendix C

Table 3. Levels of Evidence

| | Empirical Support | Social Validity |
|---|---|---|
| Strong | Strong evidence for a recommended practice requires studies with both high internal validity (i.e., studies whose designs can support causal conclusions) and external validity (i.e., studies that in total include enough of the range of participants and settings on which the recommendation is focused to support the conclusion that the results can be generalized to those participants and settings). Strong evidence for this practice guide will be operationalized as:<br>• A systematic review of research that generally meets the standards of the What Works Clearinghouse (see http://ies.ed.gov/ncee/wwc/) and supports the effectiveness of a program, practice, or approach with no contradictory evidence of similar quality; OR<br>• A sufficient number of well-designed, randomized, controlled trials or single-case research studies that meet the standards of the What Works Clearinghouse and support the effectiveness of a program, practice, or approach, with no contradictory evidence of similar quality; OR<br>• One large, well-designed, randomized, controlled, multisite trial that meets the standards of the What Works Clearinghouse and supports the effectiveness of a program, practice, or approach, with no contradictory evidence of similar quality; OR<br>• For assessments, evidence of reliability and validity that meets the Standards for Educational and Psychological Testing. | Characterization of a recommended practice as having strong social validity require that the empirical support for that practice include:<br>• Several clear demonstrations that the interventions used produced effects that met the defined clinical needs; AND<br>• Measures of stakeholder reports of acceptability of procedures, feasibility within available resources, and perceived effectiveness; AND<br>• Follow-up measures that demonstrate that typical intervention agents continue to implement procedures with fidelity after formal support is removed |
| Moderate | Evidence for a recommended practice as moderate requires studies with high internal validity but moderate external validity, or studies with high external validity but moderate internal validity. In other words, moderate evidence is derived from studies that support strong causal conclusions but where generalization is uncertain, or studies that support the generality of a relationship but where the causality is uncertain. Moderate evidence for this practice guide will be operationalized as:<br>• Experiments or quasi-experiments generally meeting the standards of the What Works Clearinghouse and supporting the effectiveness of a program, practice, or approach with small sample sizes, a limited number of single-case studies, and/or other conditions of implementation or analysis that limit generalizability, and no contrary evidence; OR<br>• Comparison group studies that do not demonstrate equivalence of groups at pretest and therefore do not meet the standards of the What Works Clearinghouse but that (a) consistently show enhanced outcomes for participants experiencing a particular program, practice, or approach and (b) have no major flaws related to internal validity other than lack of demonstrated equivalence at pretest (e.g., only one teacher or one class per condition, unequal amounts of instructional time, highly biased outcome measures); OR<br>• Correlational research with strong statistical controls for selection bias and for discerning influence of endogenous factors and no contrary evidence; OR<br>• For assessments, evidence of reliability that meets the Standards for Educational and Psychological Testing 4 but with evidence of validity from samples not adequately representative of the population on which the recommendation is focused. | Characterization of a recommended practice as having moderate social validity require the empirical support for that practice include:<br>• Several clear demonstrations that the interventions used produced effects that met the defined clinical needs; AND<br>• Measures of stakeholder reports of acceptability of procedures, feasibility within available resources, and perceived effectiveness; OR<br>• Follow-up measures that demonstrate that typical intervention agents continue to implement procedures with fidelity after formal support is removed |
| Emerging (Needs additional research) | Characterization of the evidence for a recommended practice as emerging means that the recommendation is based on expert opinion derived from strong findings or theories in related areas and/or expert opinion buttressed by direct evidence that does not rise to the moderate or strong levels. Emerging evidence is operationalized as evidence not meeting the standards for the moderate or high levels. | Practices that do not meet the standards for the strong or moderate levels will be characterized as having emerging social validity. |

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