

Self-Determination: Is a Rose by Any Other Name Still a Rose?

Ann P. Turnbull and Rud Turnbull
University of Kansas

We invite you to read this Exchange focusing on the need to have more coherence and consistency in terminology/descriptions and in anticipated outcomes related to self-determination funding. We also invite you to contribute to a national dialogue to seek the coherence and consistency for which the article advocates. You can join the online discussion by visiting the Beach Center website (www.beachcenter.org) and looking on the home page for a link to the discussion board or you may link to the discussion board through TASH.org. Please join in!

Q1

Does self-determination refer to a curriculum that teaches students with disabilities to be self-directed problem solvers, a technique for redirecting funding streams so that adults with disabilities can control the dollars allocated for their supports and services, or a philosophy grounded in democratic values and constitutional principles of autonomy and liberty? Or is it two or even all three of these? And, what terms should professionals use to inform policy leaders, practitioners, self-advocates, and families so that they will advance the self-determination cause?

One of the first times the term “self-determination” was introduced to the special education field, was the 1989 National Conference on Self-Determination sponsored by the National Institute for Disability and Rehabilitative Research. Prior to this conference, a number of researchers began to investigate the effects of choice making and self-directed learning strategies on the performance of students with severe disabilities (see Agran & Martin, 1987; Guess, Benson, & Siegel-Causey, 1985; Mithaug, Martin, & Agran, 1987; Mithaug & Hanawalt, 1978; Ward, 1988). (Note: At that time the terms “self-control” or “self-management” were used.) Shortly after that historic conference, and based on the developing body of research findings on the positive effects of self-management and self-directed learning strategies, the Office of Special Education Programs funded model programs and curriculum-development projects to promote self-determination of youths with disabilities during their secondary education (Ward,

1996; Wehmeyer, Bersani, & Gagne, 2000). Those early programs were well-documented in the literature (Wehmeyer & Sands, 1998) and laid a strong foundation for subsequent research, demonstration projects, and instructional/curriculum models. Although different definitions have emerged through the work of various research teams, the most frequently accepted definition of self-determination in the field of special education relates is: “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 1996, p. 24).

At roughly the same that self-determination models related to self-direction and problem-solving continued to expand within the field of special education, adults with disabilities began to demand greater control over their lives. Specifically, they sought to have the right to use Medicaid Home and Community-Based Services (HCBS) funds in ways that responded to their choices and needs as they themselves defined those choices and needs. In making these demands, they insisted that HCBS funds to which they are entitled were theirs to direct because they are the entitled beneficiaries – they “own” the funds – and that they, not service provider agencies, should have the right to say how the funds should be used. Moreover, they were displaying their dissatisfaction with living lives controlled by others. Their frontal challenge to the service-provider enterprise is summarized in the TASH newsletter, TASH Connections (March/April, 2005) which includes an excellent overview of policy, practices, and success stories related to this version of self-determination.

The Robert Wood Johnson Foundation funded the first demonstration project on self-determination (the term here refers to self-determination funding) at Monadnock Developmental Services in New Hampshire. This model focused on the development of individual budgets for adults with disabilities that were developed and implemented through the process of person-centered planning (Conroy, Fullerton, Brown, & Garrow, 2002).

This paper focuses on the emerging literature related to self-determination funding which holds that individuals with disabilities should have greater control over the money allocated to serve them than they have had in the past, and that service-provider agencies have now. Our purpose is to review the literature on self-determination funding to analyze terminology/

Address all correspondence and reprint requests to Ann Turnbull, Center of support for families of children with disabilities, University of Kansas Haworth Hall, Lawrence, KS 66045-7534. Email: turnball@ku.edu

descriptions and anticipated outcomes. We have two concerns that have spurred us to write this article. The first is that as students with disabilities who have had a self-determination curriculum as part of their special education curriculum move toward transition to adulthood, they are going to encounter a whole different use of the term (i.e., self-determination) as they consider funding options. Secondly, there are a wide variety of terms regarding self-determination funding that are used interchangeably, and that can unintentionally confuse stakeholders, including individuals with disabilities, families, service providers, and policymakers. For example, some of the different terms used to refer to self-determination funding include self-direction, consumer control, individual budget, and/or individualized funding (and various derivatives of each of these terms and others). In this article we present the broad range of terms/definitions and anticipated outcomes related to self-determination funding; and we invite you to a web-based discussion to express your own perspectives about what you believe the preferred terminology should be.

Table 1 contains our analysis of terminology/descriptions and anticipated outcomes of self-determination funding models as set out in 11 recent (1996–2005) documents (e.g., articles, chapters) about self-determination funding. These are all of the published articles and chapters we were able to locate that specifically address self-determination funding. (Please note that this review relates to self-determination funding, and not the substantial literature that has been published since the 1980s on self-determination related to being self-directed problem solvers.) We included direct quotes of terminology/descriptions and anticipated outcomes where possible. If the terminology/descriptions and anticipated outcomes could not be succinctly encapsulated into a single quote or two, we extracted the major concepts and highlighted those. In some cases, we needed to infer from the author's writing what he or she was intending the outcome to be since this was not explicitly stated. We highlighted key terms in italics and ordered the entries chronologically, starting in 1996 with the Robert Wood Johnson (RWJ) Foundation call for proposals for self-determination projects and continuing through the most recent 2005 publications.

As we read the 11 documents, paying particular attention to terminology/descriptions and anticipated outcomes, it became obvious that no two of these documents define key terms in exactly the same way. For example, Nerney (2005) defines self-determination primarily from a values perspective:

Self-determination for citizens with disabilities is about freedom. *Freedom* to decide how one wants to live his or her life. It's also about organizing needed *support* with the person's support network – friends, family, those who care. Self-determination

means having *authority* over resources and taking *responsibility* for decisions and action. True champions of self-determination honor the important leadership of persons with disabilities in changing our systems of support. *Confirmation* of the self-advocacy movement is a major principle of self-determination. We must not forget whose life is being lived” (p. 3).

Alternatively, Fortune and colleagues (2005) use the term *person-centered system architecture* as contrasted to the term self-determination. Furthermore, they use a functional definition rather than a values definition, but in the following passage they are generally referring to the same thing that Nerney refers to above:

Person-centered system architecture “...(1) attaches funding in the form of an individual budget to each individual; (2) gives individuals, their families, and their allies the authority to select the services and supports that reflect the person's priorities; (3) affirms uninhibited free selection of service providers; and (4) employs open (rather than slot-based) contracting to foster a market place that encourages the free entry of providers” (pp. 241–242).

Comparing and contrasting the actual terms and their descriptions highlights the potential confusion for stakeholders in encountering such discrepant nomenclature. An analysis of the entries in the left-hand column of Table 1 pertaining to terminology/description reveals that the three terms used most frequently are self-determination, individualized funding, and individual budget. Several of the more recent publications (Moseley, 2005; Moseley, Gettings, & Cooper, 2005; Stancliffe & Lakin, 2005) briefly define self-determination or self-direction but then give primary attention to the individual budget.

Our review of the anticipated outcomes (in the right-hand column in Table 1) indicates substantial consistency over time. The anticipated outcome of self-determination/individualized funding/individual budgets primarily relates to individual control (i.e., autonomy). Indeed, five of the publications explicitly identified control as the anticipated outcome. The remaining publications described outcomes in terms of related concepts such as empowerment and decision-making. Thus, there appears to be uniformity with respect to the anticipated outcome of individualized funding/ individual budgets, and that outcome is the autonomy/liberty to control one's own life.

We believe that enhancing consistency and coherence in terminology/descriptions and in the specification of anticipated outcomes is important for a couple of reasons. There is a major need to communicate as clearly as possible about the revolutionary and even transforming potential in policy and practice that redirects how public funds can (and should) be used to

Table 1
Terminology/Descriptions and Anticipated Outcomes

Terminology/Descriptions	Anticipated Outcomes
<p>1. The Robert Woods Johnson Foundation (1996) and Shumway (1999)</p> <ul style="list-style-type: none"> • <i>Self-determination</i> is based on the four principles of freedom, support, authority, and responsibility. • "...the elements of self-determination rests on the ongoing trend toward the following: <ul style="list-style-type: none"> ■ "People with disabilities and their families having a personally controlled, individual budget and the ability to determine how an individual budget will be spent..." ■ "Supports provided in the community..." ■ "Profound changes in public policy that would require new planning, operating, and financing structures..." (Shumway, 1999, p. 31). <p>2. Dowson & Salisbury (1999)</p> <ul style="list-style-type: none"> • "If [<i>individualized funding</i>]...is public funding that is allocated to the individual, based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in community as a full citizen" (p. 4). 	<ul style="list-style-type: none"> • "Self-determination is an important next step allowing persons and their families and friends, in conjunction with professionals, to be the <i>decision-makers</i> concerning the supports that are needed and how they best can be provided" (Robert Woods Johnson Foundation, 1996, p. 2).
<p>3. Aichroth et al. (2002)</p> <ul style="list-style-type: none"> • "...<i>self-determination</i> has been portrayed as...the value attributed to the autonomy of individuals [which] implies a social responsibility for cultural institutions to ensure that choice and control are available to all, not just some" (p. 17). • "<i>Self-directed services</i> are defined in this way: '...the individual, with appropriate help from the circle of support, will define what is needed, how it is provided, and from whom the service will be purchased...the person receiving support is not the direct employer-of-record' (p. 23). • "In the <i>self-managed mode</i>, the person becomes the employer-of-record for providers...in essence, they manage the money" (p. 23). 	<ul style="list-style-type: none"> • "It [<i>individualized funding</i>] gives people the freedom to develop their lives, using allocated public funds in the way that they consider best. It provides a means to ensure that plans and services will not be imposed upon them by community service providers and public officials. It provides for a process of negotiation between the individual and the holder of public funds. It also obliges service providers to treat the users as value customers and encourages the emergence of innovative services to meet their requirements" (p. 4). • "Such a perspective...allow[s] label people to make their own construction of who they are in the world, and ways in which they seek to have power and <i>control</i> over their lives" (p. 24).
<p>4. Lord & Hutchinson (2003)</p> <ul style="list-style-type: none"> • "...<i>individualized funding</i> refers to the allocation of support dollars directly to the person, in contrast to a service agency" (p. 72). 	<ul style="list-style-type: none"> • "Individualized funding allows people to <i>choose</i> where they will live, how, and who will provide support. Many individualized funding programs promote a holistic view of quality of life, looking at employment supports, community living, leisure pursuits, and relationship building" (Roehner Institute, 1997, p. 72).
<p>5. Smith (2003)</p> <ul style="list-style-type: none"> • "<i>Individualized funding and support brokerage</i>, alternatives to more traditional approaches to funding and support planning, are at the foundation of this understanding of <i>self-determination</i> and the cutting edge of the new way of thinking about supports for people with disabilities" (p. 294). 	<ul style="list-style-type: none"> • "Individualized funding approaches have substantial benefit for people with disabilities in areas of <i>personal empowerment</i>, cost effectiveness, and reducing dependence on social services" (p. 294).
<p>6. Fortune et al. (2005)</p> <ul style="list-style-type: none"> • <i>Person-centered system architecture</i> "...(1) attaches funding in the form of an individual budget to each individual; (2) gives individuals, their families, and their allies the authority to select the services and supports that reflect the person's priorities; (3) affirms uninhibited free selection of service providers; and (4) employs open (rather than slot-based) contracting to foster a market place that encourages the free entry of providers" (pp. 241–242). 	<ul style="list-style-type: none"> • "...Individuals and families would have greater <i>decision-making authority</i> in the service planning process" (p. 258).

Table 1
Continued

Terminology/Descriptions	Anticipated Outcomes
<p>7. Head & Conroy (2005)</p> <ul style="list-style-type: none"> • “Each participant was first engaged in a <i>person-centered planning process</i>... the plan was transposed into an <i>individual budget</i>...The plan and the budget were then compiled in a written <i>self-determination agreement</i>... [which] authorized the person to proceed to select, control, and direct a provider arrangement necessary to accomplish the plan” (p. 221). 	<ul style="list-style-type: none"> • “The <i>control</i> gained by individuals involved three main aspects of life. First, some individuals moved from settings that were licensed and regulated to supported independence. Second, individuals were supported and allowed to incorporate more allies into their lives. Allies were freely selected family members and friends. Third, with the support of these allies, individuals were expected to make decisions about the facets of their lives that mattered most to them. These included their jobs and other day activities, as well as other major aspects of how public funds were used” (Head & Conroy, 2005, p. 235).
<p>8. Moseley, Gettings, & Cooper (2005)</p> <ul style="list-style-type: none"> • “<i>Self-determination/consumer-direction/self-direction</i> – Belief based on the understanding that people have both the right and responsibility to exercise control over the services they receive. This belief is also based on four related principles of freedom, authority, support, and responsibility (Shumway, 1999)” (p. 265). • “<i>Individual budget</i> – A mechanism establishing an amount of funding available for an individual with disabilities to direct and manage the delivery of services he or she is authorized to receive” (p. 266). 	<ul style="list-style-type: none"> • “...<i>empower</i> individuals with disabilities to take charge of the supports they receive...” (p. 284) • “...<i>force</i> traditional systems of service delivery to change – to increase their responsiveness to consumer needs, preferences, and desires for individual <i>control</i>” (p. 284).
<p>9. Stancliffe & Lakin (2005)</p> <ul style="list-style-type: none"> • “...<i>initiatives that promote self-determination</i>...[include] having an <i>individual budget</i>, exercising control over services and decision-making, using person-centered planning, having independent support brokerage, and having a fiscal intermediary (Moseley, 2001...)” (p. 203). 	<ul style="list-style-type: none"> • “...reduction in staff control of service recipients’ lives and greater self-determination, especially regarding <i>control</i> over one’s services...” (p. 204).
<p>10. Nerney (2005)</p> <ul style="list-style-type: none"> • “Self-determination for citizens with disabilities is about freedom. <i>Freedom</i> to decide how one wants to live his or her life. It’s also about organizing needed <i>support</i> with the person’s support network – friends, family, those who care. Self-determination means having <i>authority</i> over resources and taking <i>responsibility</i> for decisions and action. True champions of self-determination honor the important leadership of persons with disabilities in changing our systems of support. <i>Confirmation</i> of the self-advocacy movement is a major principle of self-determination. We must not forget whose life is being lived” (p. 3). • “<i>Individual budget</i> was defined as the amount of funding made available to a person with developmental disabilities to enable him or her to manage and control the services she or he is authorized to receive” (p. 166). 	<ul style="list-style-type: none"> • “The purpose of self-determination is to make it possible for individuals to craft personally meaningful lives in our communities. Principles of self-determination establish that individuals with disabilities are the <i>planners</i> and <i>decision-makers</i> in how they spend their day and in how they live their lives, with caring assistance available when needed” (p. 3).
<p>11. Moseley (2005)</p> <ul style="list-style-type: none"> • “<i>Self-direction</i> or <i>self-determination</i>, the term used in many states to refer to <i>self-directed services</i>, is not a service model but rather an approach to structuring the way supports are offered. States must make several program-related structural, financial and functional changes to implement self-directed services” (p. 166). 	<ul style="list-style-type: none"> • “Three significant outcomes accompany the implementation of self-directed services. First, the shift of financial authority <i>empowers</i> individuals receiving support to act as true consumers with the ability to purchase services from the provider(s) of their choice. Second, self-directed systems of service delivery strengthen the relationship between the state as the funding entity and the persons receiving support as consumers. Third, the scope of provider agency involvement becomes <i>set by the individual</i> who has responsibility for determining the role the service provider will play in his or her life” (p. 166).

enhance individual control. The best case can be made in advocating for policy, developing model programs, and preparing youth with disabilities and their families for this type of adult support if there is a common nomenclature. It is noteworthy that the two lines of

work on self-determination – the education and the fiscal-control lines – have been carried out in a parallel fashion over the last decade, but that only two articles to date have sought to merge best practices from both lines of work (Turnbull & Turnbull, 2000; Turnbull &

Turnbull, 2001). We believe that there is mutual benefit for both lines of research on self-determination to incorporate key findings from the other line. For example, demonstration projects that are redirecting public funds to individuals with disabilities can benefit from incorporating the knowledge and skill development processes that have been documented as evidence-based practices in enhancing self-directed problem-solving. Alternatively, a way to enhance the utility and potential quality of life outcomes of self-determination skills training at the secondary level would be to prepare students (and their families) in knowledge and skill related to accessing, implementing, and monitoring individual budgets.

Terminology related to self-determination funding needs to be considered in light of the terminology to which many children and youth with disabilities and their families are introduced throughout their elementary and secondary special education program. Terminology in the lexicon of adult services should be consistent with terminology in the lexicon of schools, because the words and phrases create expectations for curriculum, behaviors (by professionals, individuals/students, and others, including their families), and outcomes (for individuals and for service systems).

We encourage you to contribute to a national dialogue to increase the coherence and consistency in terminology/descriptions and anticipated outcomes related to self-determination funding; we will work towards terms that are clear, succinct, and reflective of the values that underlie them. The Beach Center, in collaboration with AAMR and The Arc-U.S., is hosting a discussion in an online format over the next several months on the following questions:

- What are the defining characteristics of self-determination funding?
- What are the preferred outcomes of self-determination funding?
- What is the preferred terminology for self-determination funding?

To join the online discussion, please visit the Beach Center website (www.beachcenter.org), and look on the home page for the link to the discussion board, or you may link to this site through the TASH website (www.TASH.org). We will archive the results and have them available both on the Beach Center and TASH websites.

In closing we ask: Is self-determination by any other name still self-determination?

References

- Agran, M., & Martin, J. E. (1987). Applying a technology of self-control in community environments for mentally retarded individuals. In M. Hersen, R. M. Eisler, & P. M. Miller (Eds.), *Progress in behavior modification* (pp. 108–151). Beverly Hills: Sage.
- Aichroth, S., Carpenter, J., Daniels, K., Grassette, P., Kelly, D., Muray, A., Rice, J., Rivard, B., Smith, C., Smith, P., & Topper, K. (2002). Creating a new system of supports: The Vermont self-determination project. *Rural Special Education Quarterly*, 21, 16–28.
- Conroy, Fullerton, Brown, & Garrow, 2002
- Dowson, S., & Salisbury, B. (1999). *Individualized funding: Emerging policy issues*. Toronto, Canada: Roeher Institute.
- Fortune, J. R., Smith, G. A., Campbell, E. M., Clabby, R. T., II, Heinlein, K. B., Lynch, R. M., & Allen, J. (2005). Individual budgets according to individual needs: The Wyoming DOORS system. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 241–262). Baltimore: Paul H. Brookes.
- Guess, D., Benson, H. A., & Siegel-Causey, E. (1985). Concepts and issues relating to choice-making and autonomy among persons with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 10, 79–86.
- Head, M. J., & Conroy, J. W. (2005). Outcomes of self-determination in Michigan: Quality and costs. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 219–240). Baltimore: Paul H. Brookes.
- Lord, J., & Hutchinson, P. (2003). Individualized support and funding: Building blocks for capacity building and inclusion. *Disability and Rehabilitation*, 18, 71–86.
- Mithaug, D. E., Martin, J. E., & Agran, M. (1987). Adaptability instruction: The goal of transition programming. *Exceptional Children*, 53, 500–505.
- Mithaug, D. E., & Hanawalt, D. A. (1978). The validation of procedures to assess prevocational task preferences in retarded adults. *Journal of Applied Behavior Analysis*, 11, 153–162.
- Moseley, C. R. (2005). Individual budgeting in state-financed developmental disabilities services in the United States. *Journal of Intellectual & Developmental Disability*, 30, 165–170.
- Moseley, C. R., Gettings, R. M., & Cooper, R. E. (2005). Having it your way: A national study of individual budgeting practices within the states. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 263–288). Baltimore: Paul H. Brookes.
- Nerney, T. (2005). Self-determination after a decade. *TASH Newsletter*, March/April.
- Shumway, D. L. (1999). Freedom, support, authority and responsibility: The Robert Wood Johnson Foundation National Program on Self-determination. *Focus on Autism and Other Developmental Disabilities*, 14, 28–35.
- Smith, P. (2003). Self-determination and independent support brokerage: Creating innovative second-level supports. *Mental Retardation*, 41, 290–298.
- Stancliffe, R. J., & Lakin, K. C. (2005). Individual budgets and freedom from staff control. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 203–218). Baltimore: Paul H. Brookes.
- The Robert Woods Johnson Foundation (RWJF). (1996). *Call for proposal: Self-determination for persons with developmental disabilities*. Princeton, NJ: Author.
- Turnbull, A. P., & Turnbull, H. R. (2000). Achieving “rich” lifestyles. *Journal of Positive Behavior Interventions*, 2, 190–192.
- Turnbull, H. R., Beegle, G., & Stowe, M. J. (2001). The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy Studies*, 12, 133–143.

Q2

Q3

Q4

- Ward, M. (1988). The many facets of self-determination. *National Information Center for Children and Youth with Handicaps Transition Summary*, 5, 2-3.
- Ward, S. (1996). My family: Formed by adoption. *Focal Point*, 10, 30-32.
- Wehmeyer, M. L. (1996). Self-determination as an educational outcome: Why is it important to children, youth and adults with disabilities? In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 15-34). Baltimore, MD: Paul H. Brookes.
- Wehmeyer, M. L., Bersani, H., & Gagne, R. (2000). Riding the third wave: Self-determination and self-advocacy in the 21st century. In M. L. Wehmeyer & J. R. Patton (Eds.), *Mental retardation in the 21st century*. Austin, TX: Pro-Ed.
- Wehmeyer, M. L., & Sands, D. J. (1998). *Making it happen: Student involvement in education planning, decision-making, and instruction*. Baltimore: Paul H. Brookes.

AUTHOR QUERIES

AUTHOR PLEASE ANSWER ALL QUERIES

Q1 = Please provide keywords.

Q2 = For the Conroy et al., 2002, bibliographic entry, please provide the authors' initials and publication data.

Q3 = Please provide publication data for Roehrer Institute, 1997, which appeared in Table 1, and include the entry in the bibliographic list.

Q4 = For the Nerney, 2005, bibliographic entry, please provide the volume number of the newsletter and the pages in which the article appeared.

END OF AUTHOR QUERIES