


**Minnesota Governor's Council
on Developmental Disabilities**
Department of Administration

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M E M O R A N D U M

To: Members of the Public Policy Task Force on Self-Determination

From: Tara Barenok 

Subject: Self-Determination Definitions

Date: October 13, 1997

Attached are several definitions of self-determination. They vary in terms of length and breadth. Most have similar groundings in the Robert Wood Johnson Foundation language. In the interest of getting the material to you in a timely fashion, many of the definitions have been culled from readily available resources (collected materials and internet research) If you have alternative definitions or resources, please send them to me so they can be distributed to other members of the task force either at the meeting or in advance.

The contents of the packets are numbered as follows:

1. *Self Determination Defined* - a draft which compares and contrasts self-determination concepts from the Independent Living Philosophy, John O'Brien, and the Robert Wood Johnson Foundation.
2. *Minnesota's Self Determination Project* - the Department of Human Services fact sheet on self determination.
3. *Call for Proposals: Self-Determination for Persons with Developmental Disabilities* - the request from the Robert Wood Johnson Foundation to which the states responded with their proposed projects. From the Robert Wood Johnson Foundation (RWJF) web site.
4. *Beyond Managed Care: Self-Determination for People with Disabilities* - an excerpt from this publication by Thomas Nerney and Donald Shumway. It outlines the principles on Self-Determination which reoccur throughout many of the state proposals and other publications connected with the RWJF projects.
5. *Beyond Managed Care Volume II - An Owner's Manual for Self-Determination* - an excerpt from this publication by the Public Consulting Group and Self-

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Determination for Persons with Developmental Disabilities. Included are a definition of the term as well as an essay on who the "owner" in the publication title is.

6. *The Arc's Self-Determination Program* - includes an overview of the Arc's activities and a brief definition. From the Arc's home page.
7. *National Transition Alliance Student-Focused Planning and Development* - In their discussion on lifestyle planning, the NTA has embedded a definition of self-determination. From the NTA home page.

Thanks again for participating in the task force. Please contact me if you have questions or concerns. Look forward to seeing you on the 31st.

SELF DETERMINATION DEFINED

Independent Living (IL) Philosophy (1960's)	John O'Brien's 5 Valued Experiences (5 Accomplishments) (1960's)	The Four RWJ Principles that Provide the Philosophical Foundation for Systems Changes (1990's)
<ul style="list-style-type: none"> • Living like everyone else by attaining skills and receiving supports, controlled by each individual. 	<ul style="list-style-type: none"> • Sharing ordinary places (supporting community presence). 	<ul style="list-style-type: none"> • FREEDOM: the ability to plan a life with supports, rather than purchase a program.
<ul style="list-style-type: none"> • Peer support through the use of role models who mentor and provide individualized coaching that will enhance quality of life issues and ways to contribute in our communities. 	<ul style="list-style-type: none"> • Growing in relationships (supporting community participation). 	<ul style="list-style-type: none"> • AUTHORITY: the ability to control a certain sum of dollars to purchase supports.
<ul style="list-style-type: none"> • Having the right and opportunity to pursue a course of action such as being able to pursue activities of one's own choosing, limited only in the same way that one's neighbors without disabilities are limited. 	<ul style="list-style-type: none"> • Experiencing respect (supporting valued social roles). 	<ul style="list-style-type: none"> • RESPONSIBILITY: accepting a role in the community through competitive employment, organizational affiliations, and general caring for others in the community and accountability for spending public dollars in life enhancing ways.
<ul style="list-style-type: none"> • Having opportunities to make decisions that affect one's life. 	<ul style="list-style-type: none"> • Contributing (supporting contribution). 	
<ul style="list-style-type: none"> • Having the freedom to fail and to learn from one's own failure, just as people without disabilities do. 	<ul style="list-style-type: none"> • Making choices (supporting opportunities to experience choice). 	<ul style="list-style-type: none"> • SUPPORT: through use of resources, arranging formal and informal supports to live within the community.
<ul style="list-style-type: none"> • Having the right and opportunity to be a self advocate and systems change advocate at the local, state and national level to promote changes and reforms to public policies and barriers that discriminate against people with disabilities. 		
End Results?	End Results?	End Results?

Minnesota's **S**elf Determination Project

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A Developmental Disabilities Project Partnership - Blue Earth, Dakota, Olmsted Counties and DHS

FACT SHEET - FREQUENTLY ASKED QUESTIONS ABOUT MINNESOTA'S SELF DETERMINATION PROJECT

WHAT IS THE PURPOSE OF SELF DETERMINATION PROJECTS?

The purposes of self determination projects for persons with developmental disabilities are to enhance options to choose supports, housing options and employment possibilities, and improve quality of life while doing so cost effectively. The projects also create a foundation to support change and instill creative thinking for supporting persons with developmental disabilities. Emphasis is placed on individuality for supports, services, housing options and employment. Nationwide support for self determination projects has been made available through the National Office of Self Determination for Persons with Developmental Disabilities, a national program of the Robert Wood Johnson Foundation.

IS MINNESOTA THE ONLY STATE THAT IS PARTICIPATING IN A SELF DETERMINATION PROJECT?

In February 1997, Minnesota was chosen as one of 18 states to receive a self determination grant, and one of nine to receive a full three year grant of \$400,000.

IS PROJECT PARTICIPATION AVAILABLE STATEWIDE?

Currently Blue Earth, Dakota, and Olmsted counties are participating in the Project. During the three year grant period, outcomes in these locations will be evaluated to determine the feasibility of using self determination approaches statewide. All counties are encouraged to adopt self determination principles and methodologies. Information sharing and educational materials will be available statewide.

WHAT ARE THE KEY PRINCIPLES OF SELF DETERMINATION?

Freedom - The ability for individuals, with freely chosen family and/or friends, to plan and live a life with necessary support.

Support - The arranging of resources, both formal and informal, that will assist an individual to live a life he or she chooses.

Authority - Individuals will control resources, both formal and informal, that will assist them to live a life they choose.

Responsibility - Acceptance of the benefits and risks by an individual for *decisions* made, and accountability for spending public money in ways that assure health and safety and that are life enhancing.

WHAT IS THE PRIMARY FOCUS IN THE IMPLEMENTATION OF SELF DETERMINATION PRINCIPLES IN MN?

Minnesota's Self Determination Project's goal is to improve management and administration of services, service financing and design, access to services, and quality assurance.

The Project will focus on education, system redesign, and technical development for individually controlled resources.

The education component consists of assuring that consumers, their supports, and the community receive and understand information regarding self determination, how to make informed choices, person-centered planning approaches, quality assurance issues and other relative topics.

The system redesign component focuses on evaluating current regulation and policy, identifying barriers and challenges, and working on changes that are necessary to make self determination a reality for persons with developmental disabilities. Emphasis is on simplification, assuring health and safety, and supporting consumers.

Technical development for individually controlled resources will allow individuals to have control over their resources for purchasing individualized supports.

WHO IS ELIGIBLE TO PARTICIPATE?

Blue Earth, Dakota and Olmsted counties, as project participants, will select interested persons with mental retardation or related conditions to participate, for whom they are the county of financial responsibility. Selection of individuals will be based on participation criteria developed by the county.

WILL THERE BE CHANGES TO MINNESOTA RULES AND STATUTES THAT AFFECT SERVICE DELIVERY?

As part of the system redesign focus, legislation may be necessary to provide opportunities to purchase supports differently from the "status quo".

HOW IS SELF DETERMINATION DIFFERENT FROM CURRENT SERVICE DELIVERY?

Self determination allows opportunities to support persons with developmental disabilities in a manner that is individualized and creative. Although there is no single definition of self determination intervention, primarily because it is different for every individual, it provides a "new way of thinking" in respecting individualized choice and control. Current service programs that require individuals to "fit" into the programs may not allow for individualized choice or control. People grow up, live and work in communities not program systems. Adhering to the principles of freedom, support, authority, and responsibility promotes control over resources, purchasing, and decision making that can be life enhancing.

WHO IS THE PROJECT STAFF?

There is a state self determination coordinator, local site coordinators, and support staff at the Department of Human Services and at the participating counties.

Currently there is an advisory committee consisting of a parent/advocate, provider, participating county agencies and Department of Human Services staff. An expanded membership is planned in the near future to include consumers and other interested persons.

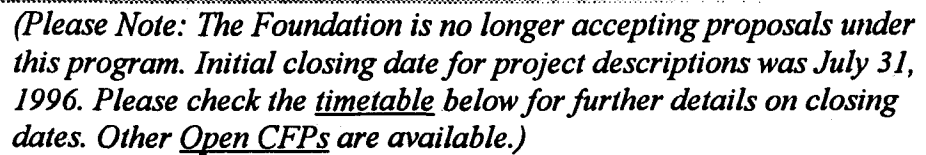
Contractors will be hired as needed to assist with problem-solving and special activities as part of the Project-wide work plan.

WILL THERE BE AN EVALUATION OF OUTCOMES FROM SELF DETERMINATION IMPLEMENTATION?

Evaluation will be on-going to assure that the goals of the Project are being met and to assess the need for change in direction and implementation. The Robert Wood Johnson Foundation also evaluates the Project.

HOW DO I GET MORE INFORMATION?

For more information contact Barb Roberts, State Self Determination Project Coordinator, (612/296-1146) or the Project county participants.



Call for Proposals: Self-Determination For Persons With Developmental Disabilities

This initiative of The Robert Wood Johnson Foundation, **Self-Determination for Persons with Developmental Disabilities**, responds to the growing interest among persons with developmental disabilities for systems of support that enable them to be contributing members of their communities. Many people with developmental disabilities have been perceived as dependent and needing long-term institutional and congregate care and treatment. Examples exist, however, in many states that demonstrate that they can be active participants in day-to-day community life. In this program, the Foundation aims to assist states and communities to transition to systems of support that recognize the abilities of persons rather than their disabilities. Up to \$5 million is available for grants to as many as 12 states to implement changes in state policy and enact reforms in at least two localities in each state. The intent is that these local initiatives will jump-start broad-based changes in states' long-term support systems for persons with developmental disabilities.

Persons with developmental disabilities include those with mental retardation, cerebral palsy, autism, and other related conditions. In recent decades the systems that support them have changed significantly. In 1967, 190,000 persons with mental retardation lived in large, usually state-sponsored institutions. Today that number has declined to fewer than 65,000. Many of the people who left the large institutions were placed in community-based programs such as group homes and sheltered workshops. These facilities often provide limited opportunity for individuals to choose where they live, with whom they live, and where they work. Many states have gone beyond deinstitutionalization and are making additional changes in their

service systems. For example, supported living has enabled persons with developmental disabilities to live in houses and apartments that they choose rather than in institutions and group homes designated for them. States' experiences with supported employment where persons with disabilities work in mainstream jobs have demonstrated that persons with severe disabilities can be productive employees.

Self-determination is an important next step allowing persons and their families and friends, in conjunction with professionals, to be the decision makers concerning the supports that are needed and how they best can be provided. The most innovative self-determination initiatives, such as the Monadnock Self-Determination Project in New Hampshire, are those in which persons and families have the chance to determine how an individual budget will be spent on housing, employment, and personal needs. An important feature of this approach integrates persons with disabilities in the life of their communities and builds informal networks of friends and family who can provide some of the day-to-day support they need. For example, a person with a disability may make a suitable arrangement with co-workers for transportation to employment -- just as non-disabled persons often do -- rather than use a separate transportation system for people with disabilities. In this way, the quality of life of persons with disabilities can be enhanced and expenditures may be reduced.

This national program offers an approach for states to improve the efficiency and effectiveness of their human service systems. Fiscal pressures are requiring states to carry out many of their same functions with fewer resources. The majority of expenditures for long-term supports are paid for by federal and state funds under the Medicaid program. Persons with developmental disabilities account for only a small percent of the total Medicaid eligible population, but the cost of long-term support services is approximately 10 percent of expenditures, or about \$15 billion a year. In addition, state-only spending is estimated at about \$5 billion a year. Despite this magnitude of expenditures, most states have growing waiting lists of persons who need supports. Many observers suggest that the high cost of the present system is due in part to the one-size fits all uniform standard of care that results in an unnecessarily expensive system. In contrast, self-determination allows individuals to purchase only what they need.

Most states are adopting managed health care in their Medicaid programs to control the cost of primary and acute health care. There is a growing interest among states to apply managed care concepts to long-term care, but so far there is little actual experience in how such principles can be appropriately adapted to finance and provide long-term supports for persons with a developmental disability. The Foundation's national program seeks to demonstrate that resources and supports can be arranged by persons with developmental

from Beyond Managed Care:
Self-Determination for people with
Disabilities, September 1996

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This paper, then, deals with options or choices that individuals with disabilities or families can make today under current regulations and laws in order to achieve self-determination. It explores both the requirements that must be met and the organizational mechanisms that might prove to be good choices. The purpose is to call for a recognition of the options that extend beyond current service delivery methods and to challenge the assumption that the sterile solution of managed care is the only or the preferred next step in this vital support system. We start with the basic principles of self-determination and then take a closer look at three organizational or reengineering issues:

- Fiscal Intermediaries or controlling dollars without dealing with cash;
- Independent brokering of supports that an individual or family may desire; and
- Organizing a coherent response in a managed care culture.

PRINCIPLES OF SELF-DETERMINATION

The following principles are meant to provide a philosophical foundation for substantive system change that incorporates the values deeply held by persons with disabilities, families and friends and advocates:

FREEDOM

The ability for individuals with freely chosen family and or friends to plan a life with necessary support rather than purchase a program;

AUTHORITY

The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;

SUPPORT

The arranging of resources and personnel--both formal and informal--that will assist an individual with a disability to live a life in the community rich in community association and contribution; and

RESPONSIBILITY

The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities.

A new way of organizing and delivering supports must be found. These four principles simply describe the conceptual basis for this approach. Each principle has important operational dimensions which should be observed without unduly restricting the forms in which these new ways of delivering supports may grow. For example, each state is organized in different ways and needs to make its own assessment of how to operationalize these principles.

Freedom in this context means that people with disabilities will have the option of utilizing public dollars to build a life rather than purchase a pre-determined program. Freedom means that individuals with disabilities, within some rational and cost-efficient system, will be able to control resources via individual budgets in order to gain the necessary experience in living and to move the dollars when their life choices change.

Authority means that individuals with disabilities really do have meaningful control over some limited amount of dollars. While many persons with developmental disabilities will

need assistance in controlling dollars and planning their lives, those chosen by the person with a disability should be ever mindful of the need to ascertain the real desires and aspirations of the person who chose them to assist.

Support is the opposite of "programming." Assisting a person with a disability to nurture informal family and friends as part of a support network is key for those who have these natural resources in place. For those who do not, creating this informal network is important and hard work. Support includes the notion of participating in the rich associational life of the person's community. One of the underlying assumptions of this principle is simply that ordinary community members, under more natural circumstances and environments, will welcome and support people with disabilities. It is important for us to remember that we have allowed public dollars to become an instrument of isolation and an artificial barrier between the person with a disability and the wider community.

Responsibility, like freedom, is a new word in our vocabulary. Both words belong in the same sentence. People with disabilities should assume responsibility for giving back to their communities, for seeking employment whenever possible, for developing their unique gifts and talents. For too long, individuals with disabilities have been seen and treated as dependent and incapable of being contributing members of our communities. The intense over-regulation of programs and the setting of goals and objectives to meet the needs of the human service system more than the aspirations of people with disabilities, have conspired to prevent people with disabilities from truly contributing to the associational life of their communities, the spiritual life of our churches and synagogues, and the cultural and artistic life of our cities and towns.

These basic principles confirm the necessity for creating structures to support their implementation. They exclude the status quo fee for service payment and program model,

as well as the managed care models that rely on networked service delivery with utilization controls. These structures must include the development of an individual budget based on a capped amount of dollars that can be used to build the supports a person needs by purchasing only what is needed and paying only for what is received. Caring social networks will become important for most individuals with disabilities, as well as the presence of independent brokerage in order to assist in both identifying and arranging necessary supports. Dollars spent can then be both invested in building a future and invested close to where the person lives.

Self-determination is not person-centered planning, although person-centered planning is a clear prerequisite for implementing these principles. Self-determination is an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system.

INDIVIDUAL BUDGETS AND FISCAL INTERMEDIARIES

Even if giving cash were an option under current regulations, it is a path fraught with danger: tax filings, unemployment insurance, complex forms to fill in and deadlines to meet--let alone the intricacies of these systems. This is not to say that cash is a bad idea for those who might desire to do this work if it ever becomes possible to use it under the federal Medicaid statute. In fact, even under a cash payment system, individuals might want to consider following the same course as those who opt for control of resources without physically receiving cash. So, under the present system, how can individuals or families gain control over dollars but not become saddled with these legal and regulatory requirements?

SECTION I: OVERVIEW OF SELF-DETERMINATION

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WHAT IS SELF-DETERMINATION?

Self-determination, from a systems management point of view, is a means by which individuals who are eligible for state developmental disabilities services (DD services) are empowered to gain control over the selection of services, or supports, that meet their own needs. The principles and values embodied in self-determination are implemented through new configurations of services and supports in combination with existing services.

Currently, consumers and providers tend to think of DD services in terms of the types of programs provided by existing organizations, such as the options for vocational training which are already available in a geographic area or the particular types of housing services available through a given organization. Self-determination is not built around particular services or programs. Rather, the self-determination approach to service delivery begins with the individual designating what kind of life activities are desired and what kinds of help are needed in order to attain those life goals within the community. Assisted, if needed, by a "circle of support," usually consisting of family, friends, and selected professionals, the individual decides what kind of service options will best meet his or her needs and life goals. While service options may be selected from choices already available through the existing service delivery system, the goal of self-determination is to allow people to create opportunities for themselves as participants in the social and economic communities in which they live.

These new opportunities make it possible for someone to participate in community organizations which have been outside the state service delivery system. For example, one young man with many disabilities, who had lived for years in a state institution, was able to move out with two friends who also served in the role of staff. Together, this three-person household created a network of friends and community participation that otherwise would not have been possible for this young man. While his happiness was greatly enhanced, the cost for his family

support subsidy was considerably less than the cost had been for his placement in the institution.

When desired services do not exist, self-determination makes it possible for an individual, with assistance, to create viable support options. For example, a young woman who was on a waiting list for a day program wanted to take art classes, but these had not been part of any available program. Self-determination made it possible for her to allocate a small budget to art lessons and membership in an art association. She was able to sell her own artwork, and when her name came up on the waiting list, to decide against placement in the day program and stick with her new career as an artist.

Self-determination demands that labels be "declinicalized," that people be considered as individuals rather than merely as recipients of services, and that the full range of supports which they need as participants in inclusive communities be available to them rather than limiting them to a narrowly defined range of services. The vision of self-determination is that persons with disabilities and their families will become able to enjoy the level of autonomous and inclusive participation in the life of their communities that most people take for granted.

PREFACE

Who Owns Self-Determination

by
Jim Piet

An essential part of self-determination is that persons with disabilities become the policy setting leaders. No one has more at stake, no one can speak to the experience as we can. Our every breath is part of the unique understanding of why self-determination is a necessity.

One's profession might be in the disability field, one might be a director of an agency and be passionate about their work with persons with disabilities. If one does not live with a disability, it is impossible to know what it takes. One should not expect to know what it takes.

As Dr. Martin Luther King Jr. stated so well;

So we have come here today to dramatize an appalling condition. In a sense we have come to our nation's capital to cash a check. When the architects of our republic wrote the magnificent words of the Constitution and the Declaration of Independence, they were signing a promissory note to which every American was to fall heir.

This note was a promise that all men would be guaranteed the inalienable rights of life, liberty, and the pursuit of happiness. It is obvious today that America has defaulted on this promissory note insofar as her citizens of color are concerned.

It is also clear that America has defaulted on this promissory note insofar as her citizens with disabilities are concerned. This is why self-determination remains fundamentally a civil rights movement.

Tokenism is rampant in this field. Much of what is said and done is a good political show; a one minute news clip before the doors close again. It is not enough to say; "Persons with disabilities have been involved in this work." In self-determination, we are the policy leaders.

All individuals engaged in policy setting need to be paid for this work. We are the consultants that know what must be done. Meaningful support for these new roles must be made available. Today, this is neither well understood nor available. But together, we have to figure out how to do this. Support costs will be high at first, but will generate productivity and declining cost throughout the service systems. As individuals become more in control of policy setting, service settings will over time become more productive operations.

The reality of self-determination will be felt when control over resources shifts; when we have the dollars that run the support systems invested in our own accounts, generating our own credit ratings, being reinvested in our community's economies and housing stock, and when we are the owners of our own supports.

There is only one way to generate good policy setting; get out and talk to people. It may take years to get to know how to communicate with one another. That is OK. There is no other way to make this happen. People must be brought to the table from all walks of life. once we realize we have similar issues our conversation will broaden and will support the reshaping of our policy.

Professionals need to look at themselves and see if they are ready for self-determination. If you are a true leader, then you will go after something greater than our old vision.

To my brothers and sisters with disabilities, I again recall for you the works of Dr. King;

You have been the veterans of creative suffering. Continue to work with the faith that unearned suffering is redemptive.

The Arc's Self-Determination Program

In 1996 The Arc of the United States established "The Arc's Self-Determination Program" within the Department of Research and Program Services. The purpose of the Self-Determination Program is "to enable The Arc, at all levels, to achieve its stated mission to "secure for all people with mental retardation the opportunity to choose and realize their goals of where and how they learn, live, work and play" by; (a) conducting model demonstration, outreach, and research projects (in conjunction with affiliated chapters) addressing self-determination, equity, and quality of life for people with mental retardation, (b) providing support to chapters, members and the public through technical support and information dissemination activities, and (c) advocating with people with mental retardation and their families to promote opportunities for self-determination and choice." The Program provides an umbrella under which The Arc's activities in the areas of self-determination, self-advocacy, educational equity, and assistive technology can be conceptualized. By elevating these activities to Program status within the organization, The Arc is both recognizing the importance of such activities and is committing to providing leadership and scholarship in this area.

Since 1990, The Arc has conducted a series of projects funded by the U.S. Department of Education to examine and support self-determination. This page provides more information about self-determination, The Arc's projects to support this outcome for people with mental retardation, and publications on this topic available from The Arc's Self-Determination Program.

What is self-determination?

We're glad you asked! We have looked at self-determination as an adult outcome. Self-determination refers to "*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, 1994). That means that people who are self-determined take control of their lives, make choices and decisions based on their interests, abilities and preferences, and take responsibility for their lives. If you want more detailed information about self-determination and the results of our research and demonstration projects, check out the self-determination publications list.

Why is self-determination an important outcome for people with mental retardation?

Self-determination is highly valued in our society. People who are self-determined make choices based on their preferences, beliefs and abilities, take control over and participate in decisions which impact the quality of their lives, take risks and assume responsibility for their actions, and advocate on behalf of themselves and others. Self-determination is one marker of adulthood, and self-determined people are viewed as worthy of respect and valued by others.

Many people with mental retardation have not had the opportunity to become self-determined or to learn the skills and have the daily experiences that will enable them to take more control and make choices in their lives. Instead, they often experience over-protection and segregation, are not included in decisions that impact their lives, and have limited opportunities to make choices as well as limited options from which to choose.

Many people assume that people with mental retardation cannot become self-determined. However, research and practice has shown that, when given adequate support, learning opportunities and experiences, people with mental retardation can learn to become more self-determined, to assume greater control over and responsibility for their lives, and can improve their quality of life. The lack of such supports, learning opportunities and experiences is, in essence, denying people with mental retardation the right to become self-determined, valued, and respected members of our communities.

What is The Arc doing to promote self-determination?

The Arc strongly supports efforts to increase opportunities for people with mental retardation to express their preferences and choices and to be self-determined. Through the activities of the Self-Determination Program, The Arc is working to enable students and adults with mental retardation and learning disabilities to become self-determined. The following provides a summary of current and past projects conducted under the auspices of the Self-Determination Program, including, when available, project outcomes, products and research findings.

Current Projects

<u>Research in Self-Determination Project</u>
<u>Promoting Choice and Self-Determination in Adults with Cognitive Disabilities</u>
<u>Gender Inequity in the Education of Students with Disabilities</u>
<u>Whose Future is it Anyway? A Transition Outreach Project</u>
<u>Assistive Technology, Self-Determination and Quality of Life Project</u>

Past Projects

<u>Self-Determination Curriculum Project</u>
<u>Self-Determination Assessment Project</u>
<u>Whose Future is it Anyway? A Self-Directed Transition Planning Program</u>
<u>Self-Determination Follow-Up Study Project</u>
<u>Assistive Technology Survey Project</u>

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National Transition Alliance

The Alliance Newsletter, Volume 1, Issue 2:

Student-Focused Planning and Development

In the last issue of the Alliance, we introduced the NTA Framework. This framework emerged from more than ten years of research conducted by the Transition Research Institute at Illinois (TRI). Its purpose facilitates the planning, development, and evaluation of school to work systems that address the needs of all students, particularly youth with disabilities. The framework features five broad categories of practices, including:

- Structures and Policies
- Student-Focused Planning and Development
- Career Pathways and Contextual Learning
- Family Involvement
- Business and Community Resources

Collaboration in all its varied forms, serves as an important connection among the categories. This article highlights practices reflected in student-focused planning and development and its contribution to effective school to work programs.

The framework, developed for the NTA, recognizes student-focused planning and development as one component of effective of effective school to work programs. Student-focused planning and development include elements that focus on planning and developing educational programs for individual students. By examining effective transition programs for youth with disabilities, TRI has distinguished six elements reflected in student-focused planning and development:

- Life Skills Instruction
- Individual Education and Career Plan Development
- Student Participation
- Planning Strategies
- Assessment
- Support Services

Life Skills Instruction includes activities in leisure skills and social skills training, self determination, and self advocacy training. Students must develop strong skills in these areas to communicate their personal interests and strengths when confronted with further education or employment opportunities. Self determination, one principle affecting success for students is defined by Ward (1988) as "the attitudes which lead people to define goals for themselves and the ability to take the initiative to achieve those goals."

Individual Education and Career Plan Development identifies measurable goals and objectives for each area of consideration: postsecondary education, vocation and community related objectives, residential, and recreational and leisure goals. Attainment of goals is reviewed annually. To ensure that effective student-focused planning occurs, *Student Participation* is a

critical component. It shifts the focus to a student driven process with documentation of student interests and preferences. Career counseling services provided to the student encourage full participation. Self-determination facilitated within the planning process paves the way for full student participation.

In *Planning Strategies*, a team including the student, family members, school and participating agency personnel, and a planning team leader must be identified. Accommodations of the student's communication needs are considered during the planning stage. Additionally, a meeting time and place conducive to student and family participation are arranged.

An authentic *Assessment* method evaluating vocational, academic, cognitive, and adaptive behavior is an integral part of student-focused planning and development. Finally *Support Services* must be in place to identify and develop environmental adaptations, accommodations, and natural support systems. Any assistive technology devices or additional related services would be added during this stage of planning.

Individualized planning is the key to effectively match a student's educational program and school experiences to his or her post-school goals. Student participation in this process is essential, and self determination skills are fundamental.

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<ul style="list-style-type: none"> • Living like everyone else by attaining skills and receiving supports, controlled by each individual. 	<ul style="list-style-type: none"> • Sharing ordinary places (supporting community presence). 	<ul style="list-style-type: none"> • FREEDOM: the ability to plan a life with supports, rather than purchase a program.
<ul style="list-style-type: none"> • Peer support through the use of role models who mentor and provide individualized coaching that will enhance quality of life issues and ways to contribute in our communities. 	<ul style="list-style-type: none"> • Growing in relationships (supporting community participation). 	<ul style="list-style-type: none"> • AUTHORITY: the ability to control a certain sum of dollars to purchase supports.
<ul style="list-style-type: none"> • Having the right and opportunity to pursue a course of action such as being able to pursue activities of one's own choosing, limited only in the same way that one's neighbors without disabilities are limited. 	<ul style="list-style-type: none"> • Experiencing respect (supporting valued social roles). 	<ul style="list-style-type: none"> • RESPONSIBILITY: accepting a role in the community through competitive employment, organizational affiliations, and general caring for others in the community and accountability for spending public dollars in life enhancing ways.
<ul style="list-style-type: none"> • Having opportunities to make decisions that affect one's life. 	<ul style="list-style-type: none"> • Contributing (supporting contribution). 	
<ul style="list-style-type: none"> • Having the freedom to fail and to learn from one's own failure, just as people without disabilities do. 	<ul style="list-style-type: none"> • Making choices (supporting opportunities to experience choice). 	<ul style="list-style-type: none"> • SUPPORT: through use of resources, arranging formal and informal supports to live within the community.
<ul style="list-style-type: none"> • Having the right and opportunity to be a self advocate and systems change advocate at the local, state and national level to promote changes and reforms to public policies and barriers that discriminate against people with disabilities. 		
End Results?	End Results?	End Results?

Minnesota's Self Determination Project

2

A Developmental Disabilities Project Partnership - Blue Earth, Dakota, Olmsted Counties and DHS

FACT SHEET - FREQUENTLY ASKED QUESTIONS ABOUT MINNESOTA'S SELF DETERMINATION PROJECT

WHAT IS THE PURPOSE OF SELF DETERMINATION PROJECTS?

The purposes of self determination projects for persons with developmental disabilities are to enhance options to choose supports, housing options and employment possibilities, and improve quality of life while doing so cost effectively. The projects also create a foundation to support change and instill creative thinking for supporting persons with developmental disabilities. Emphasis is placed on individuality for supports, services, housing options and employment. Nationwide support for self determination projects has been made available through the National Office of Self Determination for Persons with Developmental Disabilities, a national program of the Robert Wood Johnson Foundation.

IS MINNESOTA THE ONLY STATE THAT IS PARTICIPATING IN A SELF DETERMINATION PROJECT?

In February 1997, Minnesota was chosen as one of 18 states to receive a self determination grant, and one of nine to receive a full three year grant of \$400,000.

IS PROJECT PARTICIPATION AVAILABLE STATEWIDE?

Currently Blue Earth, Dakota, and Olmsted counties are participating in the Project. During the three year grant period, outcomes in these locations will be evaluated to determine the feasibility of using self determination approaches statewide. All counties are encouraged to adopt self determination principles and methodologies. Information sharing and educational materials will be available statewide.

WHAT ARE THE KEY PRINCIPLES OF SELF DETERMINATION?

Freedom - The ability for individuals, with freely chosen family and/or friends, to plan and live a life with necessary support.

Support - The arranging of resources, both formal and informal, that will assist an individual to live a life he or she chooses.

Authority - Individuals will control resources, both formal and informal, that will assist them to live a life they choose.

Responsibility - Acceptance of the benefits and risks by an individual for choices made, and accountability for spending public money in ways that assure health and safety and that are life enhancing.

**MINNESOTA'S SELF DETERMINATION PROJECT
FACT SHEET - FREQUENTLY ASKED QUESTIONS
PAGE 2**

WHAT IS THE PRIMARY FOCUS IN THE IMPLEMENTATION OF SELF DETERMINATION PRINCIPLES IN MN?

Minnesota's Self Determination Project's goal is to improve management and administration of services, service financing and design, access to services, and quality assurance.

The Project will focus on education, system redesign, and technical development for individually controlled resources.

The education component consists of assuring that consumers, their supports, and the community receive and understand information regarding self determination, how to make informed choices, person-centered planning approaches, quality assurance issues and other relative topics.

The system redesign component focuses on evaluating current regulation and policy, identifying barriers and challenges, and working on changes that are necessary to make self determination a reality for persons with developmental disabilities. Emphasis is on simplification, assuring health and safety, and supporting consumers.

Technical development for individually controlled resources will allow individuals to have control over their resources for purchasing individualized supports.

WHO IS ELIGIBLE TO PARTICIPATE?

Blue Earth, Dakota and Olmsted counties, as project participants, will select interested persons with mental retardation or related conditions to participate, for whom they are the county of financial responsibility. Selection of individuals will be based on participation criteria developed by the county.

WILL THERE BE CHANGES TO MINNESOTA RULES AND STATUTES THAT AFFECT SERVICE DELIVERY?

As part of the system redesign focus, legislation may be necessary to provide opportunities to purchase supports differently from the "status quo".

HOW IS SELF DETERMINATION DIFFERENT FROM CURRENT SERVICE DELIVERY?

Self determination allows opportunities to support persons with developmental disabilities in a manner that is individualized and creative. Although there is no single definition of self determination intervention, primarily because it is different for every individual, it provides a "new way of thinking" in respecting individualized choice and control. Current service programs that require individuals to "fit" into the programs may not allow for individualized choice or control. People grow up, live and work in communities not program systems. Adhering to the principles of freedom, support, authority, and responsibility promotes control over resources, purchasing, and decision making that can be life enhancing.

WHO IS THE PROJECT STAFF?

There is a state self determination coordinator, local site coordinators, and support staff at the Department of Human Services and at the participating counties.

Currently there is an advisory committee consisting of a parent/advocate, provider, participating county agencies and Department of Human Services staff. An expanded membership is planned in the near future to include consumers and other interested persons.

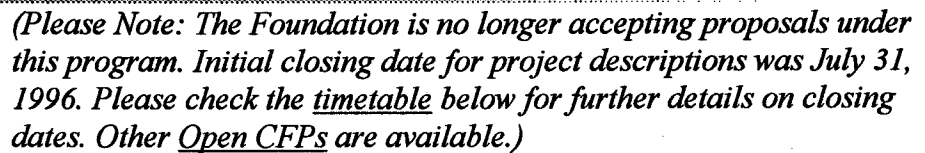
Contractors will be hired as needed to assist with problem-solving and special activities as part of the Project-wide work plan.

WILL THERE BE AN EVALUATION OF OUTCOMES FROM SELF DETERMINATION IMPLEMENTATION?

Evaluation will be on-going to assure that the goals of the Project are being met and to assess the need for change in direction and implementation. The Robert Wood Johnson Foundation also evaluates the Project.

HOW DO I GET MORE INFORMATION?

For more information contact Barb Roberts, State Self Determination Project Coordinator, (612/296-1146) or the Project county participants.



Call for Proposals: Self-Determination For Persons With Developmental Disabilities

This initiative of The Robert Wood Johnson Foundation, **Self-Determination** for Persons with Developmental Disabilities, responds to the growing interest among persons with developmental disabilities for systems of support that enable them to be contributing members of their communities. Many people with developmental disabilities have been perceived as dependent and needing long-term institutional and congregate care and treatment. Examples exist, however, in many states that demonstrate that they can be active participants in day-to-day community life. In this program, the Foundation aims to assist states and communities to transition to systems of support that recognize the abilities of persons rather than their disabilities. Up to \$5 million is available for grants to as many as 12 states to implement changes in state policy and enact reforms in at least two localities in each state. The intent is that these local initiatives will jump-start broad-based changes in states' long-term support systems for persons with developmental disabilities.

Persons with developmental disabilities include those with mental retardation, cerebral palsy, autism, and other related conditions. In recent decades the systems that support them have changed significantly. In 1967, 190,000 persons with mental retardation lived in large, usually state-sponsored institutions. Today that number has declined to fewer than 65,000. Many of the people who left the large institutions were placed in community-based programs such as group homes and sheltered workshops. These facilities often provide limited opportunity for individuals to choose where they live, with whom they live, and where they work. Many states have gone beyond deinstitutionalization and are making additional changes in their

service systems. For example, supported living has enabled persons with developmental disabilities to live in houses and apartments that they choose rather than in institutions and group homes designated for them. States' experiences with supported employment where persons with disabilities work in mainstream jobs have demonstrated that persons with severe disabilities can be productive employees.

Self-determination is an important next step allowing persons and their families and friends, in conjunction with professionals, to be the decision makers concerning the supports that are needed and how they best can be provided. The most innovative self-determination initiatives, such as the Monadnock Self-Determination Project in New Hampshire, are those in which persons and families have the chance to determine how an individual budget will be spent on housing, employment, and personal needs. An important feature of this approach integrates persons with disabilities in the life of their communities and builds informal networks of friends and family who can provide some of the day-to-day support they need. For example, a person with a disability may make a suitable arrangement with co-workers for transportation to employment -- just as non-disabled persons often do -- rather than use a separate transportation system for people with disabilities. In this way, the quality of life of persons with disabilities can be enhanced and expenditures may be reduced.

This national program offers an approach for states to improve the efficiency and effectiveness of their human service systems. Fiscal pressures are requiring states to carry out many of their same functions with fewer resources. The majority of expenditures for long-term supports are paid for by federal and state funds under the Medicaid program. Persons with developmental disabilities account for only a small percent of the total Medicaid eligible population, but the cost of long-term support services is approximately 10 percent of expenditures, or about \$15 billion a year. In addition, state-only spending is estimated at about \$5 billion a year. Despite this magnitude of expenditures, most states have growing waiting lists of persons who need supports. Many observers suggest that the high cost of the present system is due in part to the one-size fits all uniform standard of care that results in an unnecessarily expensive system. In contrast, self-determination allows individuals to purchase only what they need.

Most states are adopting managed health care in their Medicaid programs to control the cost of primary and acute health care. There is a growing interest among states to apply managed care concepts to long-term care, but so far there is little actual experience in how such principles can be appropriately adapted to finance and provide long-term supports for persons with a developmental disability. The Foundation's national program seeks to demonstrate that resources and supports can be arranged by persons with developmental

disabilities and their families and friends in ways that are cost-effective to the states and result in a higher quality of life. This consumer driven approach to managed long-term supports may provide important lessons for other populations with significant disabilities.

The program

The major objective of this Foundation program is to help states improve the quality of life of persons with developmental disabilities and to do so cost effectively. Under this program, up to \$5 million will be awarded to as many as 12 states to support changes in states' developmental disabilities systems that promote independence with supports and inclusion in the community. Grants will average \$400,000. Successful applicants will be those that initiate system changes at the state level and translate these changes into meaningful reforms for significant numbers of persons with disabilities in at least two communities in each state. Applicants should design their reforms using their own experience and interpretation of **self-determination**. But there are common activities that each state will need to consider in its reform effort, and proposals should reflect how they will be carried out. Some of the most important features of **self-determination** are:

- implementing individual budgets that will be spent based on decisions made by persons with a developmental disability, family members, and other individuals whom they choose; these individual budgets can be based for example, on a percentage of current per person costs;
- establishing individual planning, operating, and financing structures and corresponding monitoring activities consistent with the requirements of individual budgets and decentralized management;
- helping provider agencies retrain their employees to enable self-directed service brokerage;
- introducing persons with developmental disabilities and their families to the new opportunities that will be available under a reformed system, e.g., how funds can be used more flexibly to enable individuals to arrange formal and informal supports that they choose;
- rethinking state quality assurance measures to ensure their consistency with consumer and family values.

From Beyond Managed Care:
Self-Determination for people with
Disabilities, September 1996

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This paper, then, deals with options or choices that individuals with disabilities or families can make today under current regulations and laws in order to achieve self-determination. It explores both the requirements that must be met and the organizational mechanisms that might prove to be good choices. The purpose is to call for a recognition of the options that extend beyond current service delivery methods and to challenge the assumption that the sterile solution of managed care is the only or the preferred next step in this vital support system. We start with the basic principles of self-determination and then take a closer look at three organizational or reengineering issues:

- Fiscal Intermediaries or controlling dollars without dealing with cash;
- Independent brokering of supports that an individual or family may desire; and
- Organizing a coherent response in a managed care culture.

PRINCIPLES OF SELF-DETERMINATION

The following principles are meant to provide a philosophical foundation for substantive system change that incorporates the values deeply held by persons with disabilities, families and friends and advocates:

FREEDOM

The ability for individuals with freely chosen family and or friends to plan a life with necessary support rather than purchase a program;

AUTHORITY

The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports;

SUPPORT

The arranging of resources and personnel--both formal and informal--that will assist an individual with a disability to live a life in the community rich in community association and contribution; and

RESPONSIBILITY

The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities.

A new way of organizing and delivering supports must be found. These four principles simply describe the conceptual basis for this approach. Each principle has important operational dimensions which should be observed without unduly restricting the forms in which these new ways of delivering supports may grow. For example, each state is organized in different ways and needs to make its own assessment of how to operationalize these principles.

Freedom in this context means that people with disabilities will have the option of utilizing public dollars to build a life rather than purchase a pre-determined program. Freedom means that individuals with disabilities, within some rational and cost-efficient system, will be able to control resources via individual budgets in order to gain the necessary experience in living and to move the dollars when their life choices change.

Authority means that individuals with disabilities really do have meaningful control over some limited amount of dollars. While many persons with developmental disabilities will

need assistance in controlling dollars and planning their lives, those chosen by the person with a disability should be ever mindful of the need to ascertain the real desires and aspirations of the person who chose them to assist.

Support is the opposite of "programming." Assisting a person with a disability to nurture informal family and friends as part of a support network is key for those who have these natural resources in place. For those who do not, creating this informal network is important and hard work. Support includes the notion of participating in the rich associational life of the person's community. One of the underlying assumptions of this principle is simply that ordinary community members, under more natural circumstances and environments, will welcome and support people with disabilities. It is important for us to remember that we have allowed public dollars to become an instrument of isolation and an artificial barrier between the person with a disability and the wider community.

Responsibility, like freedom, is a new word in our vocabulary. Both words belong in the same sentence. People with disabilities should assume responsibility for giving back to their communities, for seeking employment whenever possible, for developing their unique gifts and talents. For too long, individuals with disabilities have been seen and treated as dependent and incapable of being contributing members of our communities. The intense over-regulation of programs and the setting of goals and objectives to meet the needs of the human service system more than the aspirations of people with disabilities, have conspired to prevent people with disabilities from truly contributing to the associational life of their communities, the spiritual life of our churches and synagogues, and the cultural and artistic life of our cities and towns.

These basic principles confirm the necessity for creating structures to support their implementation. They exclude the status quo fee for service payment and program model,

as well as the managed care models that rely on networked service delivery with utilization controls. These structures must include the development of an individual budget based on a capped amount of dollars that can be used to build the supports a person needs by purchasing only what is needed and paying only for what is received. Caring social networks will become important for most individuals with disabilities, as well as the presence of independent brokerage in order to assist in both identifying and arranging necessary supports. Dollars spent can then be both invested in building a future and invested close to where the person lives.

Self-determination is not person-centered planning, although person-centered planning is a clear prerequisite for implementing these principles. Self-determination is an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system.

INDIVIDUAL BUDGETS AND FISCAL INTERMEDIARIES

Even if giving cash were an option under current regulations, it is a path fraught with danger: tax filings, unemployment insurance, complex forms to fill in and deadlines to meet--let alone the intricacies of these systems. This is not to say that cash is a bad idea for those who might desire to do this work if it ever becomes possible to use it under the federal Medicaid statute. In fact, even under a cash payment system, individuals might want to consider following the same course as those who opt for control of resources without physically receiving cash. So, under the present system, how can individuals or families gain control over dollars but not become saddled with these legal and regulatory requirements?

SECTION I: OVERVIEW OF SELF-DETERMINATION

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WHAT IS SELF-DETERMINATION?

Self-determination, from a systems management point of view, is a means by which individuals who are eligible for state developmental disabilities services (DD services) are empowered to gain control over the selection of services, or supports, that meet their own needs. The principles and values embodied in self-determination are implemented through new configurations of services and supports in combination with existing services.

Currently, consumers and providers tend to think of DD services in terms of the types of programs provided by existing organizations, such as the options for vocational training which are already available in a geographic area or the particular types of housing services available through a given organization. Self-determination is not built around particular services or programs. Rather, the self-determination approach to service delivery begins with the individual designating what kind of life activities are desired and what kinds of help are needed in order to attain those life goals within the community. Assisted, if needed, by a "circle of support," usually consisting of family, friends, and selected professionals, the individual decides what kind of service options will best meet his or her needs and life goals. While service options may be selected from choices already available through the existing service delivery system, the goal of self-determination is to allow people to create opportunities for themselves as participants in the social and economic communities in which they live.

These new opportunities make it possible for someone to participate in community organizations which have been outside the state service delivery system. For example, one young man with many disabilities, who had lived for years in a state institution, was able to move out with two friends who also served in the role of staff. Together, this three-person household created a network of friends and community participation that otherwise would not have been possible for this young man. While his happiness was greatly enhanced, the cost for his family

support subsidy was considerably less than the cost had been for his placement in the institution.

When desired services do not exist, self-determination makes it possible for an individual, with assistance, to create viable support options. For example, a young woman who was on a waiting list for a day program wanted to take art classes, but these had not been part of any available program. Self-determination made it possible for her to allocate a small budget to art lessons and membership in an art association. She was able to sell her own artwork, and when her name came up on the waiting list, to decide against placement in the day program and stick with her new career as an artist.

Self-determination demands that labels be "declinicalized," that people be considered as individuals rather than merely as recipients of services, and that the full range of supports which they need as participants in inclusive communities be available to them rather than limiting them to a narrowly defined range of services. The vision of self-determination is that persons with disabilities and their families will become able to enjoy the level of autonomous and inclusive participation in the life of their communities that most people take for granted.

PREFACE

Who Owns Self-Determination

by
Jim Piet

An essential part of self-determination is that persons with disabilities become the policy setting leaders. No one has more at stake, no one can speak to the experience as we can. Our every breath is part of the unique understanding of why self-determination is a necessity.

One's profession might be in the disability field, one might be a director of an agency and be passionate about their work with persons with disabilities. If one does not live with a disability, it is impossible to know what it takes. One should not expect to know what it takes.

As Dr. Martin Luther King Jr. stated so well;

So we have come here today to dramatize an appalling condition. In a sense we have come to our nation's capital to cash a check. When the architects of our republic wrote the magnificent words of the Constitution and the Declaration of Independence, they were signing a promissory note to which every American was to fall heir.

This note was a promise that all men would be guaranteed the inalienable rights of life, liberty, and the pursuit of happiness. It is obvious today that America has defaulted on this promissory note insofar as her citizens of color are concerned.

It is also clear that America has defaulted on this promissory note insofar as her citizens with disabilities are concerned. This is why self-determination remains fundamentally a civil rights movement.

Tokenism is rampant in this field. Much of what is said and done is a good political show; a one minute news clip before the doors close again. It is not enough to say; "Persons with disabilities have been involved in this work." In self-determination, we are the policy leaders.

All individuals engaged in policy setting need to be paid for this work. We are the consultants that know what must be done. Meaningful support for these new roles must be made available. Today, this is neither well understood nor available. But together, we have to figure out how to do this. Support costs will be high at first, but will generate productivity and declining cost throughout the service systems. As individuals become more in control of policy setting, service settings will over time become more productive operations.

The reality of self-determination will be felt when control over resources shifts; when we have the dollars that run the support systems invested in our own accounts, generating our own credit ratings, being reinvested in our community's economies and housing stock, and when we are the owners of our own supports.

There is only one way to generate good policy setting; get out and talk to people. It may take years to get to know how to communicate with one another. That is OK. There is no other way to make this happen. People must be brought to the table from all walks of life. once we realize we have similar issues our conversation will broaden and will support the reshaping of our policy.

Professionals need to look at themselves and see if they are ready for self-determination. If you are a true leader, then you will go after something greater than our old vision.

To my brothers and sisters with disabilities, I again recall for you the works of Dr. King;

You have been the veterans of creative suffering. Continue to work with the faith that unearned suffering is redemptive.

The Arc's Self-Determination Program

In 1996 The Arc of the United States established "The Arc's Self-Determination Program" within the Department of Research and Program Services. The purpose of the Self-Determination Program is "to enable The Arc, at all levels, to achieve its stated mission to "secure for all people with mental retardation the opportunity to choose and realize their goals of where and how they learn, live, work and play" by; (a) conducting model demonstration, outreach, and research projects (in conjunction with affiliated chapters) addressing self-determination, equity, and quality of life for people with mental retardation, (b) providing support to chapters, members and the public through technical support and information dissemination activities, and (c) advocating with people with mental retardation and their families to promote opportunities for self-determination and choice." The Program provides an umbrella under which The Arc's activities in the areas of self-determination, self-advocacy, educational equity, and assistive technology can be conceptualized. By elevating these activities to Program status within the organization, The Arc is both recognizing the importance of such activities and is committing to providing leadership and scholarship in this area.

Since 1990, The Arc has conducted a series of projects funded by the U.S. Department of Education to examine and support self-determination. This page provides more information about self-determination, The Arc's projects to support this outcome for people with mental retardation, and publications on this topic available from The Arc's Self-Determination Program.

What is self-determination?

We're glad you asked! We have looked at self-determination as an adult outcome. Self-determination refers to "*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, 1994). That means that people who are self-determined take control of their lives, make choices and decisions based on their interests, abilities and preferences, and take responsibility for their lives. If you want more detailed information about self-determination and the results of our research and demonstration projects, check out the self-determination publications list.

Why is self-determination an important outcome for people with mental retardation?

Self-determination is highly valued in our society. People who are self-determined make choices based on their preferences, beliefs and abilities, take control over and participate in decisions which impact the quality of their lives, take risks and assume responsibility for their actions, and advocate on behalf of themselves and others. Self-determination is one marker of adulthood, and self-determined people are viewed as worthy of respect and valued by others.

Many people with mental retardation have not had the opportunity to become self-determined or to learn the skills and have the daily experiences that will enable them to take more control and make choices in their lives. Instead, they often experience over-protection and segregation, are not included in decisions that impact their lives, and have limited opportunities to make choices as well as limited options from which to choose.

Many people assume that people with mental retardation cannot become self-determined. However, research and practice has shown that, when given adequate support, learning opportunities and experiences, people with mental retardation can learn to become more self-determined, to assume greater control over and responsibility for their lives, and can improve their quality of life. The lack of such supports, learning opportunities and experiences is, in essence, denying people with mental retardation the right to become self-determined, valued, and respected members of our communities.

What is The Arc doing to promote self-determination?

The Arc strongly supports efforts to increase opportunities for people with mental retardation to express their preferences and choices and to be self-determined. Through the activities of the Self-Determination Program, The Arc is working to enable students and adults with mental retardation and learning disabilities to become self-determined. The following provides a summary of current and past projects conducted under the auspices of the Self-Determination Program, including, when available, project outcomes, products and research findings.

Current Projects

<u>Research in Self-Determination Project</u>
<u>Promoting Choice and Self-Determination in Adults with Cognitive Disabilities</u>
<u>Gender Inequity in the Education of Students with Disabilities</u>
<u>Whose Future is it Anyway? A Transition Outreach Project</u>
<u>Assistive Technology, Self-Determination and Quality of Life Project</u>

Past Projects

<u>Self-Determination Curriculum Project</u>
<u>Self-Determination Assessment Project</u>
<u>Whose Future is it Anyway? A Self-Directed Transition Planning Program</u>
<u>Self-Determination Follow-Up Study Project</u>
<u>Assistive Technology Survey Project</u>

Return to [The Arc's Home Page](http://thearc.org/sdet/sdet.html).

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National Transition Alliance

The Alliance Newsletter, Volume 1, Issue 2:

Student-Focused Planning and Development

In the last issue of the Alliance, we introduced the NTA Framework. This framework emerged from more than ten years of research conducted by the Transition Research Institute at Illinois (TRI). Its purpose facilitates the planning, development, and evaluation of school to work systems that address the needs of all students, particularly youth with disabilities. The framework features five broad categories of practices, including:

- Structures and Policies
- Student-Focused Planning and Development
- Career Pathways and Contextual Learning
- Family Involvement
- Business and Community Resources

Collaboration in all its varied forms, serves as an important connection among the categories. This article highlights practices reflected in student-focused planning and development and its contribution to effective school to work programs.

The framework, developed for the NTA, recognizes student-focused planning and development as one component of effective of effective school to work programs. Student-focused planning and development include elements that focus on planning and developing educational programs for individual students. By examining effective transition programs for youth with disabilities, TRI has distinguished six elements reflected in student-focused planning and development:

- Life Skills Instruction
- Individual Education and Career Plan Development
- Student Participation
- Planning Strategies
- Assessment
- Support Services

Life Skills Instruction includes activities in leisure skills and social skills training, self determination, and self advocacy training. Students must develop strong skills in these areas to communicate their personal interests and strengths when confronted with further education or employment opportunities. Self determination, one principle affecting success for students is defined by Ward (1988) as "the attitudes which lead people to define goals for themselves and the ability to take the initiative to achieve those goals."

Individual Education and Career Plan Development identifies measurable goals and objectives for each area of consideration: postsecondary education, vocation and community related objectives, residential, and recreational and leisure goals. Attainment of goals is reviewed annually. To ensure that effective student-focused planning occurs, *Student Participation* is a

critical component. It shifts the focus to a student driven process with documentation of student interests and preferences. Career counseling services provided to the student encourage full participation. Self-determination facilitated within the planning process paves the way for full student participation.

In *Planning Strategies*, a team including the student, family members, school and participating agency personnel, and a planning team leader must be identified. Accommodations of the student's communication needs are considered during the planning stage. Additionally, a meeting time and place conducive to student and family participation are arranged.

An authentic *Assessment* method evaluating vocational, academic, cognitive, and adaptive behavior is an integral part of student-focused planning and development. Finally *Support Services* must be in place to identify and develop environmental adaptations, accommodations, and natural support systems. Any assistive technology devices or additional related services would be added during this stage of planning.

Individualized planning is the key to effectively match a student's educational program and school experiences to his or her post-school goals. Student participation in this process is essential, and self determination skills are fundamental.

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