Self-Determination and Strengths-based Approaches to Disability: A Bridge for 21st Century Transitions

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A Bridge to Where?
A Bridge to Where?
“I had never had a place of my own. As a result, I had never worried about buying groceries and planning meals, paying the rent and the phone bill, balancing a checkbook, making appointments, figuring out how to keep the appointments I made – all the things adults just do. But starting out in society at the age of 28, I found these everyday tasks confusing, wonderful, and frightening.” (p. 202)
A Bridge to a Bright Future...
...or a Bridge to Nowhere?
When I grow up, I want...

...to file all day.

...to be replaced on a whim.

...to be underappreciated.

...to be paid less for doing the same job.
A Bridge to Where?
Building the Bridge: Changing How We Think About Disability
Historic Understandings of Disability

- Historically, disability was understood within a model that was an extension of the medical model, which conceived health as an *interiorized state* and health problems as an *individual pathology*; a problem within the person.

- Within such a context, disability was understood as a characteristic of the person; as residing with the person.
  - The person was seen as broken, diseased, pathological, atypical, or aberrant; as outside the norm.
  - Perhaps unavoidably, people with disabilities were, consequently, associated with numerous negative stereotypes.
Changing Understandings

- In the context of health care, it became apparent by the late 1970s that individual pathology models offered a far too narrow perspective for effectively describing, understanding, and addressing the problems of people experiencing chronic or pervasive health issues, including disability.

- In 1980, the World Health Organization introduced the International Classification of Impairments, Disabilities, and Handicaps (ICIDH).
  - The ICIDH perspective for describing the impact of a health condition or pathology on human functioning were: (a) the exteriorization of a pathology in body anatomy and functions; (b) objectified pathology as expressed in the person’s activities (e.g. adaptive behavior skills), and (c) the social consequences of pathology (e.g. participation in social life domains).

- Later, (ICF, 2001) it was recognized that besides the impact of health condition factors (pathology), contextual and environmental factors are of pivotal importance for understanding human functioning.
  - Human functioning is best understood in the context of a person-environment fit or interaction model.
Changing Expectations:
Changing Understanding

Disability

Personal Incompetence
Changing Expectations: Changing Understanding

Personal Competence

Environment
Changing Expectations: Changing Understanding

Disability

Personal Competence

Environment
Implications of Changing Understandings of Disability

- Strengths-based
- Focus on environment/context, not fixing individual;
- Emphasizes supports, not programs
Supports

- Resources and strategies that:
  - promote the interests and causes of individuals with or without disabilities;
  - enable them to access opportunities, information, and relationships inherent within integrated work and living environments;
  - result in enhanced interdependence, productivity, community inclusion, life satisfaction, and human functioning.

- Personalized array of supports
An Array of Supports

- Specialized Services
- Generic Services
- Nonpaid Supports
- Family & Friends
Implications for the Education of Students with Disabilities

- A focus on supplementary aids and services.
- Access to the general education curriculum and Universal Design for Learning.
- A focus on self-determination and student-directed learning
- Assistive technology and accommodations.
- Electronic and information technology.
- Supported employment, supported living.
- Multitiered systems of supports
- Personalized learning
**Personalized Learning**

- Changing understandings of disability and advances in technology are moving us toward a system focused on personalized learning.

- Personalized learning environments are characterized by:
  - An emphasis on student-directed learning
  - Integration of technology into all aspects of the learning experience
  - Promotes student choice and self-determination
  - Repeated assessment through the learning experience.
Personalized Learning

- Digital Talking Books.
- Smartphones, iPads, & Tablet PCs
- Cloud-based apps
- 3D Printing
- The Internet of Everything
Implications for Transition Services

- From Career Development to Life Design
  - “Career theories and vocational guidance techniques must be reformulated to fit the post-modern economy” (Savickas et al., 2009, p. 240).
  - “Theoretical models are needed that emphasize human flexibility, adaptability, and life-long learning...” (Savickas et al, 2009, p. 240).
  - Life-designing emphasizes enabling young people to become experts in ‘constructing’ their own career paths, taking on transitions, addressing threats and opportunities, and designing a better life (Nota & Rossier, 2009).

- From Special Education to Secondary Education


Implications for Transition Educators

• Presume competence.
• Promote self-determination.
• Involve young people in planning for their future.
• Emphasize goal setting and problem solving.
• Consider the role of hope, optimism, resilience, coping, and so forth in the lives of young people with disabilities.
Building the Bridge: Self-Determination
Transition Principles for Empowerment

- Transition interventions should be designed to be maximally under the control of the individual, rather than others;
- Transition interventions should be designed to facilitate individual independence and autonomy;
- The least restrictive means that are still effective should be used; and
- The most natural interventions for the particular work environment should be used.
What is Self-Determination?

Self-Determination is a dispositional characteristic manifested as acting as the causal agent in one’s life. Self-determined people (i.e., causal agents) act in service to freely chosen goals. Self-determined actions function to enable a person to be the causal agent in his or her life.

*Causal agency:* To make or cause something to happen in one’s life.

*Volitional action:* Making a conscious choice or decision with deliberate intention.
The philosophical doctrine of determinism posits that actions are caused by events or natural laws that precede or are antecedent to the occurrence of the action. Behavior, then, is governed by these other events or natural laws.
Self-Determination and Determinism

- Self-determinism, or self-determination, implies that individuals *cause* themselves to act in certain ways, as opposed to someone or something else ‘causing’ us to act in certain ways.

- People who are self-determined embody the characteristic or quality of ‘self-determination,’ a noun referring to the degree to which that person acts or behaves in ways that are self- (instead of other-) caused.
Self-Determination and Disability

- Within the context of the disability rights and advocacy movement, the construct as a personal characteristic has been imbued with the empowerment and “rights” orientation typically associated with the sense of the term as a national or political construct. Empowerment is a term usually associated with social movements, and typically is used, as Rappaport (1981) stated, in reference to actions that “enhance the possibilities for people to control their lives” (p. 15).
Self-Determination and Disability

"People with autism should be treated with the same dignity, respect, and equality as people without autism.” Jean-Paul Bovee

"We don't have to be told what self-determination means. We know it is just another word for a life filled with rising expectations, dignity, respect and opportunities.“ Robert Williams
What Do We Know About Self-Determination?

• People with disabilities are less self-determined than their non-disabled peers.
  • Seems clear that this is primarily because people with disabilities have fewer opportunities to make choices and express preferences across their daily lives.
• The environments in which people with disabilities live, learn, and work limit the development of self-determination.

• IQ is positively correlated (r=.15 to .20) with self-determination, but not predictive of self-determination status (high vs. low SD group).
  • IQ is predictive of where one lives/works, which in turn is predictive of self-determination status.
• Choice-making opportunities vary across environments, but those opportunities are strong predictors of self-determination status.
• Self-determination status predicts membership in higher quality of life groups.
What Do We Know About Self-Determination?

• Adolescents with disabilities who leave school as self-determined young people:
  • Are more independent one year after graduation.
  • Are more likely to live somewhere other than where they lived in high school one year after graduation.
  • Are significantly more likely to be employed for pay at higher wages one year after graduation.
  • Are significantly more likely to be employed in a position that provides health care, sick leave, and vacation benefits three years after graduation.
  • Are significantly more likely to live independently three years after

• Adults with disabilities rank self-determination as more important than do professionals and parents/family members.

• Teachers working with students with disabilities report that:
  • they are familiar with self-determination;
  • believe self-determination is an important component of education;
  • believe that student involvement in education planning is important;

• Parents of school-age students with disabilities perceive promotion of self-determination as important.
  • Report that they do not believe that their sons/daughters receive enough instruction on component elements of self-determined behavior at school.
What Do We Know About Self-Determination?

- Despite wide acceptance of the importance of self-determination, research has consistently found that explicit instruction to promote self-determination is limited.
  - Educational goals addressing self-determination are not included on many educational programs.
- Research identifies as barriers to the promotion of self-determination:
  - Teacher beliefs about whether the student will benefit tied to student level of disability;
  - Insufficient training to and knowledge about promoting self-determination.
- Meta-analytic (group and single-subject design) studies show that students with disabilities can acquire component elements if taught.
  - Student-directed learning strategies particularly powerful.
- Research documents that students with disabilities are not actively engaged/involved in educational planning meetings.
  - Research has also shown that students with disabilities can learn the skills to be active participants in their education planning meetings.
- Research suggests that student involvement has a reciprocal effect with self-determination. That is, students who are more self-determined are more likely to be involved in their educational planning, but getting students involved in their planning— independent of their level of self-determination—enhances self-determination.
Comparisons of Self-Determination among Students with Autism, Intellectual Disability, and Learning Disabilities: A Multivariate Analysis*

- Validated The Arc’s Self-Determination Scale with youth with autism spectrum disorders**
- Examined differences in self-determination among middle and high school students with autism spectrum disorders (n = 70), intellectual disability (n = 72), and learning disabilities (n = 74).


Comparisons of Self-Determination among Students with Autism, Intellectual Disability, and Learning Disabilities: A Multivariate Analysis

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>ASD</th>
<th>ID</th>
<th>LD</th>
<th>p₁</th>
<th>p₂</th>
<th>p₃</th>
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</thead>
<tbody>
<tr>
<td>The Arc’s Self-Determination Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy</td>
<td>53.52 (4.04)</td>
<td>60.25 (3.81)</td>
<td>62.24 (3.94)</td>
<td>.05</td>
<td>.01</td>
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<tr>
<td>Self-Regulation</td>
<td>10.48 (1.18)</td>
<td>9.16 (1.11)</td>
<td>11.19 (1.15)</td>
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<td>ns</td>
<td>.04</td>
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<td>Psychological Empowerment</td>
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<td>11.82 (.61)</td>
<td>13.01 (.63)</td>
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<td>.04</td>
<td>.02</td>
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<td>Self-Realization</td>
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<td>9.82 (.65)</td>
<td>11.07 (.67)</td>
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<td>ns</td>
<td>.02</td>
</tr>
</tbody>
</table>

Estimated Group Means and Results of Pairwise Comparisons

Note. M (SE). ASD = autism, ID = intellectual disability, LD = learning disabilities. p₁ = p value for comparing ASD vs. ID, p₂ = p value for comparing ASD vs. LD, p₃ = p value for comparing ID vs. LD.
Five Year Longitudinal Study (Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013)

- Purpose: Examine the effects of interventions to promote self-determination
- Randomized trial, placebo control group design study
- 50 school districts in six states (Arkansas, Kansas, Missouri, Nebraska, Oklahoma, and Texas)
- Students with diverse disability labels and their teachers participated
- Student’s school campuses were randomly assigned to a treatment or control group

Participants

• 493 middle and high school students

• Age
  – Range: 11-22 years
  – Mean: 16 years (SD 2.2)

• Disability
  – Learning Disability – 31%
  – Intellectual Disability – 27%
  – Other Health Impairment – 11%
  – Emotional/Behavioral Disorder – 9%
  – Autism – 5%
  – Other – 17%

• Gender
  – Female – 36%
  – Males – 64%

• Race/Ethnicity
  – Native American – 1%
  – Asian – 2%
  – African American – 19%
  – White – 60%
  – Hispanic – 18%
  – Other – 1%
Interventions

• The ChoiceMaker Curriculum (with The Self-Directed IEP materials)
  – Martin, Marshall, Maxson, & Jerman, 1993

• NEXT S.T.E.P. Curriculum
  – Halpern, Herr, Doren, & Wolf, 2000

• Self-Advocacy Strategy
  – Van Reusen, Bos, Schumaker, & Deshler, 2002

• Self-Determined Learning Model of Instruction
  – Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000

• Steps to Self-Determination (2nd Ed.)
  – Hoffman & Field, 2005

• Whose Future is it Anyway? (2nd Ed.)
  – Wehmeyer, Lawrence, Kelchner, Palmer, Garner, & Soukup, 2004
Self-Determination Intervention Efficacy Study

- Subset of the Sample from the overall NIDRR Study
  - High School Students
  - With Disability Labels of
    - Learning Disability
    - Intellectual Disability
- Outcome Measures
  - The Arc’s Self-Determination Scale (SDS; Wehmeyer & Kelchner, 1995)
  - The AIR Self-Determination Scale (AIR; Wolman et al., 1994)
- Data collected over a three year period
  - Baseline, End of Year 2, End of Year 3
Research Question

- Do interventions designed to promote self-determination lead to improvement in the self-determination scores of students with disabilities?
  - Multi-level latent growth curve models (LGMs)
    - IV: Treatment Group, Disability, Gender
    - DV: The Arc’s Self-Determination Scale, AIR Self-Determination Scale
Findings

The Arc’s Self-Determination Scale

[Graph showing the comparison of Control and Intervention groups over 3 years with increasing scores over time.]
Follow-Along Study: Self-Determination and Adult Outcomes

<table>
<thead>
<tr>
<th></th>
<th>Estimate</th>
<th>S.E</th>
<th>P-value</th>
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<tbody>
<tr>
<td>Community Access – 1 Year Post*</td>
<td>1.078</td>
<td>0.293</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Community Access – 2 Years Post</td>
<td>0.948</td>
<td>0.363</td>
<td>&lt; .001</td>
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<tr>
<td>Employment – 1 Year Post*</td>
<td>0.504</td>
<td>0.215</td>
<td>.01</td>
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<tr>
<td>Employment – 2 Years Post</td>
<td>0.238</td>
<td>0.208</td>
<td>.25</td>
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<tr>
<td>Financial Independence – 2 Years Post</td>
<td>-0.449</td>
<td>0.214</td>
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</table>
Two Year Study of SDLMI

Two Year Longitudinal Study of the impact of the *Self-Determined Learning Model of Instruction*

- Randomized trial, modified placebo control group design study
- 20 school districts participated in three states (Kansas, Missouri, and Texas)
- Students with intellectual disability and learning disabilities and their teachers participated
- Student’s school campuses were randomly assigned to a treatment or control group
Intervention

• Self-Determined Learning Model of Instruction
  – Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000
• During Year 1 of the project, teachers at treatment campuses were trained in the SDLMI
  – Teachers at control campuses continued with typical instruction
  – Year 1 provided a pretest-posttest control group comparison study
• During Year 2, teachers on control campuses were trained in the SDLMI in the same fashion
  – Teachers at treatment campuses continued implementing the SDLMI with participating students
  – All students received intervention in Year 2.
Research Questions

• Are there differences in the latent self-determination means of students assigned to the control group and the treatment group over time as a function of exposure to the SDLMI?

• Do students with intellectual disability and learning disabilities who receive instruction using the SDLMI show greater attainment of academic and transition goals than students who do not receive instruction using the Self-Determined Learning Model of Instruction?

• Do students with intellectual disability and learning disabilities who receive instruction using the SDLMI show enhanced access to the general education curriculum compared to students who do not receive such instruction?
### Key Findings: Impact on Self-Determination

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>Latent d</th>
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<tr>
<td><strong>M (95% C.I.)</strong></td>
<td><strong>M (95% C.I.)</strong></td>
<td><strong>M (95% C.I.)</strong></td>
<td><strong>M (95% C.I.)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>AIR Self-Determination Scale</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Intervention Group</td>
<td>.00 (.00 – .00)</td>
<td>.07 (-.17 – .31)</td>
<td><strong>.30 (.08 – .52)</strong>*</td>
<td>.31</td>
</tr>
<tr>
<td>Control Group</td>
<td>.16 (-.10 – .42)</td>
<td>.11 (-.15 – .37)</td>
<td>.17 (-.10 – .44)</td>
<td>.01</td>
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<tr>
<td>Latent d</td>
<td>-.20</td>
<td>-.05</td>
<td>.14</td>
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<td><strong>The Arc’s Self-Determination Scale</strong></td>
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<tr>
<td>Intervention Group</td>
<td>.00 (.00 – .00)</td>
<td>-.06 (-.21 – .10)</td>
<td><strong>.24 (.06 – .42)</strong>*</td>
<td>.24</td>
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<tr>
<td>Control Group</td>
<td>-.01 (-.27 – .25)</td>
<td>-.06 (-.32 – .21)</td>
<td>.03 (-.26 – .33)</td>
<td>.05</td>
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<tr>
<td>Latent d</td>
<td>.01</td>
<td>.00</td>
<td>.23</td>
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### Key Findings: Goal Attainment

Least Square Means for Disability*Treatment Groups for Academic and Transition GAS Scores

<table>
<thead>
<tr>
<th></th>
<th>Academic GAS Scores</th>
<th>Transition GAS Scores</th>
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<tr>
<td></td>
<td>Mean</td>
<td>SE</td>
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<tr>
<td>Learning Disability - Control</td>
<td>44.78</td>
<td>1.79</td>
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<tr>
<td>Learning Disability – Treatment</td>
<td>50.51*</td>
<td>1.63</td>
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<tr>
<td>Intellectual Disability - Control</td>
<td>48.07</td>
<td>0.98</td>
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<tr>
<td>Intellectual Disability – Treatment</td>
<td>48.30</td>
<td>1.15</td>
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</table>
### Key Findings: Impact on Access to the General Education Curriculum

Estimates for Access Score Intercept and Slopes for the Disability and Treatment Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>Access Score at the Beginning of the Year (SE)</th>
<th>Access Score at the End of the Year (SE)</th>
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<tbody>
<tr>
<td><strong>Control</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>2.2 (.44)</td>
<td>3.3 (.49)</td>
</tr>
<tr>
<td>Learning Disability</td>
<td>3.3 (.24)*</td>
<td>3.4 (.26)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>2.5 (.51)</td>
<td>4.6 (.52)†</td>
</tr>
<tr>
<td>Learning Disability</td>
<td>3.6 (.35)*</td>
<td>5.1 (.37)*†</td>
</tr>
</tbody>
</table>
A Self-Made Man by Raymond J. Gagne

“My name is Raymond J. Gagne. This is a true story. I was born on January 10, 1945 in Attleboro, Massachusetts. I am a person with cerebral palsy” (p. 327).
Eight Years of Power

- My mother felt there was something wrong with me. She took me to many doctors and hospitals to see if they knew how to help me. They told my mother I would never walk.

- When I was home, I used to sit in a rocking chair next to a yellow window. My brothers and sisters went to school. At the time, there was no school for me.

- **When I was 8, my mother told me I was going away.**
A Life of No Power: Eighteen Years in an Institution

- After arriving at the state school, I was put in Building 7.
- Every morning we would wake up at 6:00. An attendant would help me put on the clothes he had laid out the night before. I didn’t have any say about what I wore.
- The staff never seemed to prepare me for living outside the institution. They didn’t seem to think I would make it on my own. Up until the age of 14, I wasn’t allowed to go to school.
Twenty Years in the Real World: A Struggle for Power

- The day I moved out, some staff told me I would be back in a month. They may be still waiting for me to come back.
- That same year I went on a vacation to Washington, D.C. by myself. This was the first time I had ever done this.
- During the fall I moved into my own apartment after a counselor at a camp for people with cerebral palsy told me she thought I could.
Twenty Years in the Real World: A Struggle for Power

- I learned about Section 504 of the Rehabilitation Act and helped found a self-advocacy group. I learned the skills of leadership, advocacy, consumer organizing and assertiveness by watching people, participating in group meetings and asking questions. My ability to communicate my ideas and to facilitate work toward changing the status quo developed over time.
Unlike the staff at the institution, the human services professionals I met at this job treated me with respect. They gave me a chance to contribute my input and feedback and believed in many of my ideas. My colleagues also adapted the working environment to help me communicate with them.
Twenty Years in the Real World: A Struggle for Power

- I wrote this story to let people know what it was like growing up in an institution from the 1950s through the 1970s. The total lack of power in making decisions about my life made me angry and I was treated as an outcast. I feel that what has happened to me should never happen again.