Why is Promoting Self-Determination Important?
Implications for the Education of Students with Disabilities

- Access to the general education curriculum and Third Generation Inclusive Practices
- Universal Design for Learning.
- Supported employment, supported living.
- Multi-Tiered Systems of Support
- A focus on self-determination and student-directed learning
The SWIFT Center

SCHOOLWIDE INTEGRATED FRAMEWORK FOR TRANSFORMATION
Multi-Tiered Systems of Support

Academic Instruction (with fidelity measures)

Level 3
Tertiary Interventions (for individual students)
• Assessment Based
• Resource Intensive

Level 2
Secondary Interventions (for some students: at-risk)
• Some Individualizing
• Small Group Interventions
• High Efficiency
• Rapid Response

Level 1
Primary Interventions (for all students)
• Preventive, Proactive
• Differentiated Instruction
• Research-Validated Curriculum

Behavioral Instruction (with fidelity measures)

Level 3
Tertiary Interventions (for individual students)
• Wraparound Intervention
• Complex Multiple Life Domain Functional Behavior Assessment and Behavior Intervention Plans

Level 2
Secondary Interventions (for some students: at-risk)
• Some Individualizing
• Small Group Interventions
• High Efficiency
• Rapid Response

Level 1
Primary Interventions (for all students)
• Direct Instruction of Behavioral Expectation
• Positive Acknowledgment

Universal Screening All Students

Technological Assistance Center for Inclusive School-wide Reform
SWIFT: The Schoolwide Integrated Framework For Transformation Center

KU The University of Kansas
College and Career Readiness for Students with Significant Cognitive Disabilities
Who are Students with Significant Cognitive Disabilities?

- The [U.S.] Department [of Education] intended the term “significant cognitive disabilities” to include that small number of students who are (1) within one or more of the existing categories of disability under the IDEA [Individuals with Disabilities Education Act] (e.g., autism, multiple disabilities, traumatic brain injury, etc.); (2) whose cognitive impairments may prevent them from attaining grade-level achievement standards, even with the very best instruction (p. 23).
The Myth of Readiness; or: Why Flow-through Models Fail Students with Significant Cognitive Disabilities

“Pre- means never.”
Lou Brown

Emergence of Supported Employment
This Matters

Postsecondary Education for Students with Intellectual and Developmental Disabilities
Educating Students with Significant Cognitive Disabilities

- There is an overwhelming body of evidence that students with severe disabilities can learn and progress.
- Jerome Bruner (1966) defined instruction as [simply] "an effort to assist or to shape growth" and theories of instruction as theories of "how growth and development are assisted by diverse means" (p. 1).
- There are a wide variety of instructional strategies and techniques that have been validated with this population.
Principles of Instruction for Students with Significant Cognitive Disabilities

- **Principle of Ultimate Functioning**
  - Instruction should focus on instruction in ecologically valid, naturally occurring environments that will be the ultimate environment in which the student is to function.

- **Principle of Maximal Participation**
  - Students have the right to participate in activities that contribute to the quality of their life to the maximum degree possible.

- **Principle of Partial Participation**
  - Even if students cannot acquire all the skills that are required to function independently in an environment, they should have access to that environment and enabled to learn those skills that they are able to acquire.

- **Presumed Competence**
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.
Determining an Evidence Base

- U.S. Department of Education, Office of Special Education Programs Evidence-based Practice Initiative
- National Secondary Transition Technical Assistance Center EBP summary
- What Works in Transition Research Synthesis Project
Determining an Evidence Base

- Follows Taxonomy for Transition Programming* framework introduced by Paula Kohler (Western Michigan University)
- Five Transition Domains
  - **Student Development:** Includes strategies in life skills instruction, career and vocational curricula, structured work experience, and assessment.
  - **Student-Focused Planning:** Includes practices in the areas of IEP development, student participation in planning, and planning strategies.
  - **Interagency Collaboration:** Includes practices in the areas of collaborative frameworks and collaborative service delivery.
  - **Family Involvement:** Includes practices in family training, family involvement, and family empowerment.
  - **Program Structure:** Includes practices in program philosophy, policy and evaluation, strategic planning, resource allocation, and human resource development.

Levels of Evidence

- **Strong**
  - Multiple quality group experimental design studies and/or single subject design studies and sufficient effect sizes from meta-analytic studies.

- **Moderate**
  - A few quality group experimental design studies and/or single subject design studies, multiple correlational studies, some systematic synthesis of findings

- **Potential**
  - One acceptable quality group experimental design or 1 to 2 high quality single subject designs or 1 to 2 correlational studies.

- **Low**
  - Descriptive studies, case studies, program evaluation studies only.
Evidence Base: Student Development

- **Strong Evidence for Practices:**
  - Teaching Functional Life Skills
  - Teaching Purchasing Skills
  - Teaching Self-Advocacy Skills
  - Teaching Self-Determination Skills

- **Moderate Evidence for Practices**
  - Teaching Functional Reading/Math Skills
  - Teaching Independent Living (banking, cooking, food preparation, grocery shopping, recreation, etc.) skills.
  - Teaching life skills via community-based instruction
  - Teaching job-related social/communication skills
  - Teaching job specific employment skills.
  - Teaching job application skills
  - Teaching self-management for employment skills
Evidence Base: Student-Focused Planning

- **Strong Evidence for Practices:**
  - Teaching self-advocacy skills
  - Teaching self-determination skills

- **Moderate Evidence for Practices**
  - Involving students in transition planning meetings
# NSTTAC Evidence-based Practices in Secondary Transition

## Table 1.1 Evidence-based practices in secondary transition

<table>
<thead>
<tr>
<th>Kohler's taxonomy category</th>
<th>Evidence-based practices</th>
</tr>
</thead>
</table>
| **Student-focused planning** | • Involving students in the IEP process  
• Using the Self-Advocacy Strategy  
• Using the Self-Directed IEP |
| **Student development** | • Teaching: functional life skills  
• banking skills  
• restaurant purchasing skills  
• employment skills using CAI  
• grocery shopping skills  
• home maintenance  
• leisure skills  
• personal health skills  
• job-specific employment skills  
• purchasing using the “one more than” strategy  
• life skills using CAI  
• life skills using CBI  
• self-care skills  
• safety skills  
• self-determination skills  
• self-management for life skills  
• self-management for employment  
• self-advocacy skills  
• purchasing skills  
• functional reading skills  
• functional math skills  
• social skills  
• purchasing skills  
• completing a job application skills  
• job-related social communication skills  
• cooking and food preparation skills  
• employment skills using CBI |
| **Family involvement** | • Training parents about transition services |
| **Program structure** | • Providing community-based instruction  
• Extending services beyond secondary school  
• Using Check and Connect |
| **Interagency coordination** | • none |

*Source: Used by permission (public domain), National Secondary Transition Technical Assistance Center (2010).*
### NSTTAC Evidence-based Predictors of Success

**Table 1.2** Evidence-based predictors of post-School Employment, Education and Independent Living Success

<table>
<thead>
<tr>
<th>Predictors/outcomes</th>
<th>Education</th>
<th>Employment</th>
<th>Independent living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Career awareness</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Community experiences</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Exit exam requirements/</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma status</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Inclusion in general education</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Interagency collaboration</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational courses</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid employment/ work experience</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Parental involvement</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program of study</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>Self-advocacy/self-determination</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>Self-care/independent living</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Social skills</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student support</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Transition program</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational education</td>
<td>X</td>
<td></td>
<td>X</td>
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<tr>
<td>Work study</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Source: Used by permission (public domain), National Secondary Transition Technical Assistance Center (2010).*
Massachusetts Student-Driven Secondary Transition Model
Self-Determination and People with Intellectual and Developmental Disabilities: What Does the Research Tell Us?

There exists an already substantive and still growing literature base pertaining to self-determination and people with disabilities. The intent of this slide show is to provide a synthesis of major findings in the area of self-determination pertaining to youth and adults with intellectual and developmental disabilities.
What Does the Research Tell Us About Promoting Self-Determination?

Studies included in the review met these selection criteria:

- The researchers measured global self-determination, as opposed to one component (such as choice making or problem solving only), using a validated measure of self-determination. By measuring “global self-determination,” we mean that the research must have actually measured self-determination using a valid measure of self-determination.

- The studies included in the review had to involve adults/students with disabilities.

Finding Summary: Self-Determination Status

- Research shows that youth/adults with intellectual disability are less self-determined than their non-disabled peers.
  - It is important, however, not to assume that this in any way reflects the capacity of people with disabilities to become self-determined. The research clearly shows that people with intellectual disability have many fewer opportunities to make choices and express preferences across their daily lives.
Finding Summary: Factors Contributing to Self-Determination

- Social abilities and adaptive behavior skills are related to more positive self-determination.
- Choice-making opportunity is a strong predictor of self-determination. Research shows that the environments in which adults with disabilities live or work limit opportunities to make choices and restrict personal autonomy.
- Although many people believe that people with intellectual disability cannot be self-determined because of their cognitive impairment, research consistently shows that while SD is positively correlated with IQ, that relationship is generally weak and IQ is not predictive of self-determination status.
  - IQ is predictive* of where one lives/works, which in turn is predictive of self-determination status by virtue of the above-noted findings.

*By predictive, we simply mean the research shows a statistical relationship between IQ and where one lives/works. This should not be interpreted to mean that IQ must, by any means, be predictive of where one lives or works; it is simply the case at the current time.
Finding Summary: Self-Determination and Adult Outcomes

- Multiple research studies find that a person’s self-determination status predicts higher quality of life.
- Self-determination status is positively correlated with more positive post-secondary outcomes, including employment, independent living, and community inclusion for youth with disabilities.
- Young adults who are more engaged in personally-valued recreation activities are more self-determined, suggesting a reciprocal relationship between recreation activities and self-determination.
Finding Summary: Self-Determination and Adult Outcomes (continued)

- Students with cognitive 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 graduation.
Finding Summary: Perceptions of Self-Determination and People with Disabilities

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

- Special education teachers report that:
  - they are familiar with self-determination;
  - believe self-determination is an important component of transition planning;
  - believe that student involvement in planning is important;
  - their level of training, students’ type and level of disability, and type of teaching placement impact their ratings of the importance of promoting self-determination.

- 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.
Finding Summary: Efforts to Promote Self-Determination

- Despite wide acceptance of the importance of self-determination, research has consistently found that explicit instruction to promote self-determination during the school years is limited, though more recent studies suggest that this situation may be changing.

- Teachers report that barriers to promoting self-determination include:
  - Their belief about whether the student will benefit;
  - Insufficient time, particularly in context of No Child Left Behind;
  - Insufficient training to and knowledge about promoting self-determination.
  - Insufficient time to plan to integrate instruction to promote self-determination into the instructional day.
Finding Summary: Efficacy of Interventions to Promote Self-Determination

- Data exists to support the efficacy of several self-determination-focused intervention models/programs, including:
  - Steps to Self-Determination (Hoffman & Field, 1995)
  - TAKE CHARGE for the Future (Powers et al., 2001)
  - Self-Determined Learning Model of Instruction (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000)

- Meta-analytic (group and single-subject design studies) of existing research show that students with disabilities can acquire component elements of self-determined behavior (e.g., choice making, decision making, problem solving, goal setting and attainment, self-advocacy, self-regulation, perceptions of efficacy, self-awareness, self-knowledge) if taught.
  - Student-directed learning strategies particularly powerful.
Finding Summary: Self-Determination and Student Involvement

- Research has shown that students with disabilities are not major players in their IEP/transition planning meetings.
- Research has also shown that students with disabilities can learn the skills to be active participants in their IEP/transition 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.
Finding Summary: Self-Determination and Student Involvement (continued)

- Data exists to support the efficacy of the following student—involvement related interventions/programs:
  - Next S.T.E.P. (Halpern, et al., 1997)
  - Self-Directed IEP (Martin, Huber Marshall, Maxon, & Jerman, 1997)
  - Self-Advocacy Strategy (VanReusen et al., 2002).
  - Whose Future is it Anyway? (Wehmeyer et al., 2005).
Limitations in the Knowledge Base

• None of the aforementioned studies provided evidence of a causal relationship between intervention to promote self-determination and enhanced student self-determination.
  • Important for both intervention purposes and construct validity purposes
• Need more evidence pertaining to the effect of specific interventions on self-determination.
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
Whose Future Efficacy Study

- Outcome Measures
  - The Arc’s Self-Determination Scale (SDS; Wehmeyer & Kelchner, 1995)
  - The AIR Self-Determination Scale (AIR; Wolman et al., 1994)
  - Whose Future Is It Anyway-Knowledge Test (Wehmeyer & Lawrence, 1995)

- Data
  - Year 1 – Pre/Post for Control and Treatment Group
  - Students with Intellectual Disability
Research Questions

• Does the Whose Future Curriculum significantly impact the self-determination outcomes of students with disabilities?
  – Repeated Measures MANCOVA
    • IV: Time, Treatment Group
    • DV: Self-Determination
    • Covariates: Intellectual Capacity, Time Spent with Special Education Teacher

• Does instruction using the Whose Future Curriculum lead to improvement in transition knowledge and skills?
  – Repeated Measures MANCOVA
    • IV: Time, Age Group (Middle / High)
    • DV: Self-Determination, Whose Future is it Knowledge Test
    • Covariates: Intellectual Capacity, Time Spent with Special Education Teacher
Key Findings

- Does the Whose Future Curriculum significantly impact the self-determination outcomes of students with disabilities?
  - Self-determination increased significantly over time for both groups, but the change was significantly greater for students in the treatment group
  - Direct supervision was not a significant covariate, but IQ level was
  - Replicated at the univariate level

- Does instruction using the Whose Future Curriculum lead to improvement in transition knowledge and skills?
  - Transition knowledge and skills increased over time for all students in the treatment group
  - No significant differences between changes over time for middle and high school group
  - No significant covariates
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 Arc’s Self-Determination Scale over time. The graph indicates a trend of increasing scores from year 1 to year 3, with separate lines for Control and Intervention groups.]}
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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</thead>
<tbody>
<tr>
<td>Community Access – 1 Year Post*</td>
<td>1.078</td>
<td>0.293</td>
<td>&lt; .001</td>
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<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>
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<td>Employment – 2 Years Post</td>
<td>0.238</td>
<td>0.208</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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</tbody>
</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>
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<tr>
<td><strong>AIR Self-Determination Scale</strong></td>
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<tr>
<td>Intervention</td>
<td>.00 (.00 – .00)</td>
<td>.07 (-.17 – .31)</td>
<td>.30 (.08 – .52)*</td>
<td>.31</td>
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<td>Group</td>
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<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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<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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<td>Intervention</td>
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<td>-.06 (-.21 – .10)</td>
<td>.24 (.06 – .42)*</td>
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<tr>
<td>Control Group</td>
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<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>
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</table>
### 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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<tbody>
<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>
</tr>
<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 Self-Determination

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>Control</td>
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<tr>
<td>Intellectual Disability</td>
<td>2.2 (.44)</td>
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<td>Learning Disability</td>
<td>3.3 (.24)*</td>
<td>3.4 (.26)</td>
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<td>Treatment</td>
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<td>Intellectual Disability</td>
<td>2.5 (.51)</td>
<td>4.6 (.52)†</td>
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<tr>
<td>Learning Disability</td>
<td>3.6 (.35)*</td>
<td>5.1 (.37)†</td>
</tr>
</tbody>
</table>

* Indicates significance at the p < 0.05 level.
† Indicates significance at the p < 0.01 level.
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.
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.
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.