

CAPABILITY AND INDEPENDENCE SCALE (CAIS)©

*A Personalized Diagnostic and
Planning Tool to Ease and
Support Youth through Post
School Outcomes*

*Tested and Used in school
planning, employment, and in
vocational rehabilitation*

 Jackie Marquette Ph.D.

Preface

The transition years for adolescents and young adults are often met with resistance and uncertainty. As their new roles emerge, parents are often in a state of urgency for solutions. The Capability and Independence Scale can be helpful for anyone who has an autism spectrum disorder (ASD) or developmental disability (DD). More youth than ever are moving through the educational system and in need of services and supports that will help them move into post high school life. In regard to students with Autism Spectrum Disorders, more youth are being diagnosed and will need specialized support.

Transition plans are designed during the last few years of school, and within the plan, significant issues are often left out and pertinent information not addressed. That is "what comes next?" Many families fear their son/daughter's transition phase because families cannot see beyond high school graduation. What they do see is frightening scenarios posted on internet list serves or in the media. Their fears are understandable because few examples exist of young adults with autism spectrum disorders and developmental disabilities experiencing success and a quality of life. In essence there is nothing tangible to see or hope to see.

Transition has two faces, the school side and post high school adult life. What promise does the later phase of transition hold for youth? Parents question, "Where will this school transition plan carry my son? my daughter? What does the other side of transition hold for my son? our family? Many parents may not ask these questions outwardly, but do so inwardly. I know this well because I have lived through the many negative and uncertain effects of the transition phase with my son Trent who has autism.

There is good news among all this uncertainty. Daily living for the individual can be filled with increased responsibility and new experiences which deliver setbacks, and yes, personal growth. Life can become enriching and more enjoyable than all the school years combined. How do I know this? Because I have lived it and I have interviewed many families who have also lived these experiences. They shared with me their choices, actions to guide their young adult, and beliefs that drove their efforts. Indeed, successful outcomes do not just happen, it requires positive energy in planning, making decisions, and commitment toward action.

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Trent and I endured the challenges of his isolation and obsessive behaviors that increased with significant changes within the family and in his own life. Despite the isolation and obsessions, we helped him acquire employment and independent living. Trent is now 30 years old, has been successfully living independently with a roommate for over six years, and has held a 20 hour a week job at a large retail store working in the Pets Department. All occurred with necessary built-in supports.

The idea to design the CAIS emerged from recognizing the intricate needs and supports within my work with students who had severe disabilities and my experience raising a son with autism. I questioned, explored, tested, then retested, studied and personally lived it with Trent. My previous work:

- reading quality of life research articles on people with disabilities within the past 23 years,
- searching and applying tools and strategies through trial and error of approaches other students and families used and,
- conducting research and discovering results from my doctoral study which consisted of 15 young adults with an Autism Spectrum Disorder (ASD) who achieved independent living, employment, enjoyment, and acceptance in activities within the community.

The findings revealed certain themes that were shared: similar perspectives, initiatives, practices, and resilience. Action steps along with risk taking and a certain amount of emotionally "letting go" of the young adult led to the individual's experiencing positive outcomes in employment, problem solving, attending college, making choices, living independently, advocating, and developing associations and friendships. Again these results do not come naturally, that is, without effort, supports by family, close associations, and collaboration with school and agency personnel.

I offer the CAIS scale to you the parent, family member, advocate, and professional who are concerned and want to learn more about how to help youth with ASD and DD reach a quality of life that is uniquely h/her own. I hope you find the CAIS helpful as you guide a student to reach a life with purpose (i.e. employment, attending school, enjoying leisure, volunteer work, and acceptance with greater independence in the community), and growth even with disability challenges. Most importantly, the intent of using the CAIS is to provide the

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advocate tools when used appropriately that can promote the individual's personal growth in seven domains of living. Lastly, the goal for individuals with disabilities is to find enjoyment in life through the process of failure, endurance with support, and increased personal growth.

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Capability and Independence Scale (CAIS)

Instructions

On the following pages, RATE the five questions in each of the seven domains of life activities. CIRCLE the number from 1-9 on the scale that best represents the level of functioning for the adult with a developmental disability, under BOTH conditions:

- a. Rate the individual's capability on his/her own.
- b. Rate the individual's capability with support/assistance.

Use the following 9-point scale. The even numbers represent positions midway between the odd-numbered descriptors.

Levels of Capability

9 = capable of functioning and living independently; i.e. like the vast majority of the population.

8

7 = *occasional* assistance, guidance, or supervision needed; particularly for periods of *stress* on specific issues such as *legal/financial* matters.

6

5 = *some* assistance needed for *most* functions; Supervision needed for specific issues like *legal/financial* and *complex* matters, *ongoing* support for daily routines.

4

3 = *considerable* assistance needed to learn and perform *most* skills; Can do *simple* tasks if provided assistance or *close* supervision.

2

1 = *extensive* assistance needed *all* the time; can learn and perform *simple* task with *continuous* supervision.

Supports can range from the simple reminders or visits check on his or her well being, to explicit check lists or a calendar of daily activities, to the extensive with a live-in assistant, ongoing supervision at work, technical monitoring device or phones. Support is always tailored to each person's needs. You can find a list of supports in Appendix C.

Capability and Growth Score Sheet

Name:

Date:
(First Admin.)

Date:
(Follow-up)

	Gen. Funct/ Life Skills		Cognitive Ability		Community Life/ Social		Occupation Capability		Domestic/ House hold Life		Emotional Stability		Communication		Overall Enhance- ments
DATE	IND	W/S	IND	W/S	IND	W/S	IND	W/S	IND	W/S	IND	W/S	IND	W/S	
1.															
2.															
3.															
4.															
5.															
Domain Capability Function															

Capability and Growth Score Sheet

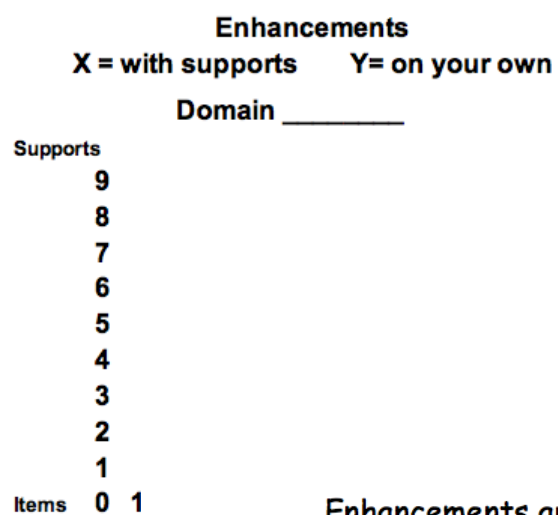
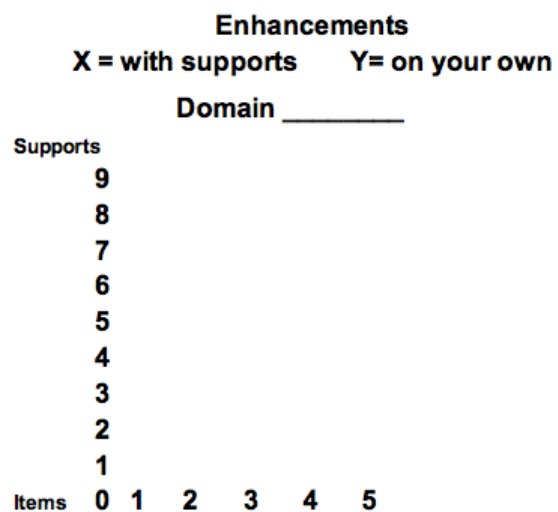
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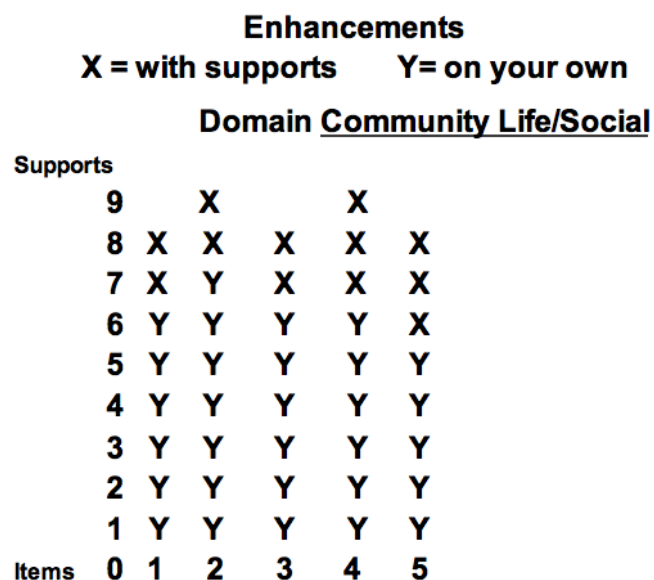
Date: 4/09
(Follow-up)

	Gen. Funct/ Life Skills		Cognitive Ability		Community Life/ Social		Occupation Capability		Domestic/ House hold Life		Emotional Stability		Communication		Overall Enhance- ments
DATE	IND 10/ 06	W/S 4/09	IND	W/S	IND	W/S	IND	W/S	IND	W/S	IND	W/S	IND	W/S	
1.	3	7	7	9	6	8	6	8	5	9	4	7	3	7	
2.	3	7	3	7	7	9	3	7	7	8	3	5	4	7	
3.	2	9	3	5	6	8	7	9	7	9	3	5	3	6	
4.	6	9	3	8	6	9	6	9	7	9	5	8	5	7	
5.	2	9	5	7	5	8	6	8	6	8	6	9	4	7	
Domain Capability Function	3.2	8.2	4.2	7.2	6	8.4	5.6	8.2	6.4	8.6	4.2	6.8	3.8	6.8	

Enhance- ments W/S -IN	+5	+3	+2.4	+2.6	+2.2	+2.6	+3	20.8
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Enhancements are shown below on a graph as an example. The graph illustrates the individual's capability with "independence" (on your own) and "with supports." The visual indicates where the student's independence levels end and supports begin lifting h/her to participate at higher capability levels.



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