# 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



### 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.

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

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	l Independence	Scale ©	Jackie M.	Marquette
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			D. Occupational	capability on his/ her own	capability with support/assistance
Capabil	lity and Independence Sc	ale 🛭 Jackie	1. Exhibits willingness to learn		
	Rate the individual's	Rate the	new skills/tasks on job.	123456789	123456789
C. Community Life/ Social	capability on his/ her	capability support/a			
			2. Accepts redirection		
<ol> <li>Accommodates new situations, change, or</li> </ol>			or a correction by co- workers or supervisor.	123456789	123456789
challenging events.	123456789	12345(	workers or supervisor.		
			3. Gets along with and socialize with co-workers, e.g., breaks		
2. Adjusts or adapts to unfamiliar people.	123456789	123456	on the job.	123456789	123456789
3. Participates in community life, e.a., movies, sports,			Follows instructions and wor independently when	ks	
festivals, church, or civic organizations.	123456789	123456	necessary.	123456789	123456789
			5. Evaluates task completion.	123456789	123456789
<ol> <li>Shops and decides what to buy.</li> </ol>	123456789	123450			
5. Accepts and responds to feedback about behavior in social situations.	123456789	123450			

1. Accor situat challe Capability and Independ Rate the indivi capability on h own B. Cognitive/Intellectual

Capabil

Does daily errands,
 e.g., going to bank, to doctor
 or to SSI office (excluding
 transportation needs).

Considers options and makes choices.

Uses transportation system, e.g., automobile, bicycle, or public transportation.

Participates with family and close friends in a variety of everyday and/or holiday activities.

5. Participates in budgeting and goal setting, e.g., Person-Centered Planning or family meetings.

1. Understands and uses oncertains unuses
strategies for routine
management, e.g., calendar,
daily schedules,
checklists, or pictures. 12345678

Consumes information, e.g., reading, listening, computer, or observing.
 12345678

3. Understands jokes, sarcasm, figures of speech, etc. 12345678

12345678

Passes test(s) for employment, education, or self-improvement, etc.

5. Thinks about and solves problems. 12345678

Capability and Independence Scale © Jackie M.

12345678

12345678

12345678

12345678

12345678

E. Domestic/Household Life capability on his/ her capability with support/assist

123456789

123456789

Maintains personal hygiene through self care.

Takes responsibility for tasks--caring for pets, cleaning, trash, laundry, recycling, etc.

2. Participates in food selection, preparation, and clean up. 123456789

4. Takes responsibility for own health and wellness—nutrition, medications, etc. 123456789

5, Chooses among home entertainment options, e.g., TV programming, internet, or games. 1 2 3 4 5 6 7 8 9

Capability and Independence Scale S Jackie M. Marquette

F.	Emotional Stability	Rate the individual's capability on his/ her own	Rate the individual's capability with support/assistance
1.	Interprets other people's feelings and emotions appropriately.	123456789	123456789
_			
2.	Feels or expresses emotion		
	for personal accomplishment or loss.	123456789	123456789
_	behavior, or peer pressure by others.	123456789	123456789
4.	Uses self talk or relaxation to avoid obsessive/ compulsive or aggressive		
	behaviors.	123456789	123456789
5.	Demonstrates compassion by helping others, e.g., grand- parents, family members, or		
	persons with special needs.	123456789	123456789

Capability and Independence Scale © Jackie M. Marquette Rate the individual's Rate the individual's

31

6. Communication	capability on his/her own	capability with support/assistance
Initiates or responds to greetings or to ongoing conversations.	123456789	123456789

Asks for help when needed; reports illness or		
emergency.	123456789	123456789

3. Expresses own though	ts and		
desires clearly.	123456789	123456789	
			-

communicate with fa		
friends.	123456789	123456789

<ol><li>Responds appropriately</li></ol>		
to non-verbal communic	ation	
social cues, gestures,	facial	
expressions, etc.	123456789	123456789

Name:					Сар	Date			D	Score ate: Follow-up									
DATE	Gen. Funct/ Life Skills		Funct/		Cognitive Ability				Comm Life/ Socia	unity I	Occup Capat	pation pility	Dome: House hold L		Emot Stab		Commu	nication	Overall Enhance- ments
	IND	W/5	IND	W/5	IND	W/S	IND	W/5	IND	W/5	IND	W/5	IND	W/5					
1.																			
2.																			
3.																			
4.																			
5.																			
Domain Capability Function																			

# Capability and Growth Score Sheet Date: 10/06 (First Admin.) Date: 4/09 (Follow-up)

Name:

	Gen. Fund Life		Cogn Abili	itive ity	Commu Life/ Social	inity	Occup Capab		Domes House hold L			Emotional Stability		tability		Overall Enhance- ments
DATE	IND 10/ 06	W/S 4/09	IND	W/S	IND	W/S	IND	W/S	IND	W/5	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

### **Enhancements** X = with supports Y = on your ownDomain \_\_\_

Supports 9 8 7 6 0 1

#### **Enhancements**

X = with supports Y= on your own

Domain \_

Supports 9 8 7 6 5 3 2 1 0 1 Items

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.

### **Enhancements**

X = with supports Y= on your own

Domain Community Life/Social

Supports

X 8 X X X X X Y X X X X YY Υ Υ Υ Υ 2 Items 0 1

# FONT AND GRAPHIC CREDITS

















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