Case Studies

Case Study 1: Darlene Simmons

Darlene Simmons, 35 years old, lives with a roommate in an apartment with needed supports. Ms. Simmons and her roommate are both employed part time approximately 20 hours per week. Although Ms. Simmons has held several jobs in the past, including work in a restaurant, a bank, and a florist shop, she has worked for the past 3 years in the billing department of a hardware store. Her job is to help mail statements and to sort and deliver mail to offices within the store. Ms. Simmons is friendly with her co-workers and was named "employee of the month" during June of her second year on the job. After work, she often takes the city bus to the Escapade music store where she likes to look for used CDs to listen to at home and share with her friends.

Ms. Simmons attended a local high school until she was 22 years of age. She received employment training in the community in the afternoon while attending classes in functional academics and vocational training in the morning. Most of her jobs had been obtained through connections made during her employment training or through friends of her family. She lived with family until she was 25, and then she moved first to a group home and then to her current supported-living apartment. Ms. Simmons has had the same roommate, Vicky Elliston, for the past 2 years. They both receive weekly assistance from their community service provider to pay their bills, manage their budgets, make necessary medical appointments, and update any records needed to maintain their assistance. Ms. Simmons and Ms. Elliston get support weekly from family members for grocery shopping, cleaning their apartment, and laundering their clothes. Several nights a week they eat dinner with a family member. The rest of the week they purchase their lunch at work or cook prepackaged food in their microwave oven.

Ms. Simmons has an IQ score in the range of 51–60 (WAIS-III), adaptive behavior (ABS) needs in the mild range, and has low vision, which has been corrected to a functional level with glasses. She would like to get contact lenses, but she is squeamish about inserting them in her eyes. She can read signs in the community, uses her basic sight-word reading vocabulary to keep up with her favorite celebrities in magazines she buys at the drug store, and uses a calculator to budget her income from her job and her monthly SSI check with the assistance of her service provider or a family member. Recently Ms. Simmons has become an active participant in the newly formed "special recreation" organization in the city parks department of her community. She especially likes the weekly swing dances at the community center and is glad the community service agency provides transportation to and from the dances. And, of course, she is happy that her parents are willing to pay her monthly phone bill. (What would she do if she were unable to gossip with girlfriends about which men showed up at the dance and who was the best looking partner and the best dancer?) She wishes that the "special rec." would have an-

other play on the stage at the local community center with actors both from special rec. and their friends from the community. Last time there was a play, she had a speaking part and had her picture taken with the whole cast. She is also taking a class at the community center to help her learn how to say no to strangers who approach her on the bus or in the store and to improve her ability to tell her doctor and other medical people what she needs and if she is feeling all right.

All in all, Ms. Simmons considers herself to be "independent" and "on her own." After all, some of her friends from high school are still living with their parents and do not even have a job. Ms. Simmons, on the other hand, can choose to go straight home from work if she wants, go shopping for CDs after work, or stop for a coffee and bagel before heading home. With plenty of friends and family around to help her if she needs it, life on her own is just right for Ms. Simmons. See Figure 3.5 for the completed *SIS* and Scoring Form for Case Study 1.

Supports Intensity Scale

Interview and Profile Form

Adult Version (ages 16 and up)

99MT62

ID/TRACKING NUMBER

Name ___Simmons___ ___Darlene___ ___B.___
         LAST   FIRST   MIDDLE

Address ___1105 Lancaster Drive___

City, State, Zip ___Chicago Heights, IL 60411___

Phone ___708 / 555 / 3032___ Language Spoken at Home ___English___

Individuals or Organizations Providing Essential Supports:

Name ___William & Ruthie Simmons___ Relationship ___Parents___ Phone ___708 / 555 / 8333___

Name ___Jackie Delmonte___ Relationship ___Residential Services Counselor___ Phone ___708 / 555 / 3000___

Name ___Angelina Rodriguez___ Relationship ___Vocational Services Counselor___ Phone ___708 / 555 / 1961___

Other Pertinent Information ___Receives services from Outlook, Inc. and supported employment___

Date *SIS* Completed

___2003___ / ___10___ / ___13___ /
  YR   MO   DAY

Date of Birth ___1968___ / ___08___ / ___04___ /
             YR   MO   DAY

Age ___35___

Gender ☐ Male ☒ Female

Respondent Name	Relationship to Individual	Language Spoken
1. William & Ruthie Simmons	Parents	English
2. Jackie Delmonte	Residential Counselor	English
3. Angelina Rodriguez	Vocational Counselor	English

Interviewer ___Melissa Anderson___ Position ___Case Manager___

Agency/Affiliation ___Dept. of Human Services___ Phone ___708 / 555 / 3724___

Address ___1217 Marion, Chicago Heights, IL 60911___ Email ___Mander@dhs.state___

James R. Thompson, PhD   David A. Rotholz, PhD
Brian R. Bryant, PhD   Robert L. Schalock, PhD
Edward M. Campbell, PhD   Wayne P. Silverman, PhD
Ellis M. Craig, PhD   Marc J. Tassé, PhD
Carolyn M. Hughes, PhD   Michael L. Wehmeyer, PhD

aaidd
American Association
on Intellectual and
Developmental Disabilities

Figure 3.5. Completed *SIS* for Darlene Simmons.

Section 1. Support Needs Scale

INSTRUCTIONS: Identify the Frequency, Daily Support Time, and Type of Support that is reported necessary for the person to be successful in the six activity domains (Parts A–F). **Circle the appropriate number (0–4) for each measurement** (i.e., Frequency, Daily Support Time, Type of Support). (See rating key below.) Add across each line item to obtain the Raw Scores. Sum the Raw Scores down to obtain the Total Raw Score for each Part.

1. This scale should be completed without regard to the services or supports currently provided or available.

2. Scores should reflect the supports that would be necessary for this person to be successful in each activity.

3. If an individual uses assistive technology, the person should be rated with said technology in place.

4. Complete ALL items, even if the person is not currently performing a listed activity.

Part A: Home Living Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Using the toilet	⓪	1	2	3	4	⓪	1	2	3	4	⓪	1	2	3	4	0
2. Taking care of clothes (includes laundering)	0	1	②	3	4	0	1	②	3	4	0	1	2	③	4	7
3. Preparing food	0	1	②	3	✕	0	1	②	3	4	0	1	2	③	4	7
4. Eating food	⓪	1	2	3	4	⓪	1	2	3	4	⓪	1	2	3	4	0
5. Housekeeping and cleaning	0	1	②	3	4	0	1	②	✕		0	1	2	③	4	7
6. Dressing	⓪	1	2	3	4	⓪	1	2	3	4	⓪	1	2	3	4	0
7. Bathing and taking care of personal hygiene and grooming needs	⓪	1	2	3	✕	⓪	1	2	3	4	⓪	1	2	3	4	0
8. Operating home appliances	0	1	②	3	4	0	①	2	3	4	0	1	②	3	4	5

TOTAL Raw Score Home Living Activities: 26

Enter the Raw Score (max. = 92) on the *SIS* Profile, on page 8, Section 1A, Part A, Home Living Activities

RATING KEY

FREQUENCY:
How frequently is support needed for this activity?
0 = none or less than monthly
1 = at least once a month, but not once a week
2 = at least once a week, but not once a day
3 = at least once a day, but not once an hour
4 = hourly or more frequently

DAILY SUPPORT TIME:
On a typical day when support in this area is needed, how much time should be devoted?
0 = none
1 = less than 30 minutes
2 = 30 minutes to less than 2 hours
3 = 2 hours to less than 4 hours
4 = 4 hours or more

TYPE OF SUPPORT:
What kind of support should be provided?
0 = none
1 = monitoring
2 = verbal/gestural prompting
3 = partial physical assistance
4 = full physical assistance

2

Supports Intensity Scale, Section 1. ©AAIDD

Section 1. Support Needs Scale, continued

Circle the appropriate number (0–4) for each measurement. (See rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part B: Community Living Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Getting from place to place throughout the community (transportation)	0	1	(2)	3		0	(1)	2	3	4	0	(1)	2	3	4	4
2. Participating in recreation/leisure activities in the community settings	0	1	(2)	3		0	1	(2)	3	4	0	(1)	2	3	4	5
3. Using public services in the community	0	1	(2)	3		0	(1)	2	3	4	0	(1)	2	3	4	4
4. Going to visit friends and family	(0)	1	2	3		(0)	1	2	3	4	(0)	1	2	3	4	0
5. Participating in preferred community activities (church, volunteer, etc.)	(0)	1	2	3		(0)	1	2	3	4	(0)	1	2	3	4	0
6. Shopping and purchasing goods and services	0	1	(2)	3	4	0	1	(2)	3	4	0	(1)	2	3	4	5
7. Interacting with community members	(0)	1	2	3	4	(0)	1	2	3	4	(0)	1	2	3	4	0
8. Accessing public buildings and settings	0	1	(2)	3	4	0	(1)	2	3	4	0	1	(2)	3	4	5

TOTAL Raw Score Community Living Activities: 23

Enter the Raw Score (max. = 91) on the *SIS* Profile, on page 8, Section 1A, Part B, Community Living Activities

Part C: Lifelong Learning Activities	Frequency					Daily Support Time					Type of Support (TS)					Raw Scores
1. Interacting with others in learning activities	(0)	1	2	3		(0)	1	2	3	4	(0)	1	2	3	4	0
2. Participating in training/ educational decisions	0	(1)	2	3		0	(1)	2	3		0	(1)	2	3	4	3
3. Learning and using problem-solving strategies	0	(1)	2	3	4	0	(1)	2	3	4	0	(1)	2	3	4	3
4. Using technology for learning	0	1	(2)	3	4	0	(1)	2	3	4	0	(1)	2	3	4	4
5. Accessing training/educational settings	0	1	(2)	3	4	0	(1)	2	3	4	0	(1)	2	3	4	4
6. Learning functional academics (reading signs, counting change, etc.)	(0)	1	2	3	4	(0)	1	2	3	4	(0)	1	2	3	4	0
7. Learning health and physical education skills	0	1	(2)	3	4	0	(1)	2	3	4	0	(1)	2	3	4	4
8. Learning self-determination skills	0	1	(2)	3	4	0	(1)	2	3	4	0	1	(2)	3	4	5
9. Learning self-management strategies	0	1	(2)	3		0	(1)	2	3	4	0	1	(2)	3	4	5

TOTAL Raw Score Lifelong Learning Activities: 28

Enter the Raw Score (max. = 104) on the *SIS* Profile, on page 8, Section 1A, Part C, Lifelong Learning Activities

Supports Intensity Scale, Section 1. ©AAIDD

3

Section 1. Support Needs Scale, continued

Circle the appropriate number (0–4) for each measurement. (See rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part D: Employment Activities

Activity	Frequency	Daily Support Time	Type of Support	Raw Scores
1. Accessing/receiving job/task accommodations	(0) 1 2 3	0 (1) 2 3 4	0 1 (2) 3 4	3
2. Learning and using specific job skills	0 (1) 2 3	0 (1) 2 3 4	0 (1) 2 3 4	3
3. Interacting with co-workers	(0) 1 2 3	(0) 1 2 3 4	(0) 1 2 3 4	0
4. Interacting with supervisors/coaches	(0) 1 2 3	(0) 1 2 3 4	(0) 1 2 3 4	0
5. Completing work-related tasks with acceptable speed	0 (1) 2 3	0 (1) 2 3 4	0 (1) 2 3 4	3
6. Completing work-related tasks with acceptable quality	0 (1) 2 3	0 (1) 2 3 4	0 (1) 2 3 4	3
7. Changing job assignments	(0) 1 2	0 (1) 2 3 4	0 (1) 2 3 4	2
8. Seeking information and assistance from an employer	(0) 1 2 3	(0) 1 2 3 4	0 (1) 2 3 4	1

TOTAL Raw Score Employment Activities: 15

Enter the Raw Score (max. = 87) on the *SIS* Profile, on page 8, Section 1A, Part D, Employment Activities

Part E: Health and Safety Activities

Activity	Frequency	Daily Support Time	Type of Support	Raw Scores
1. Taking medications	(0) 1 2 3 4	(0) 1 2 3 4	(0) 1 2 3 4	0
2. Avoiding health and safety hazards	0 (1) 2 3 4	0 (1) 2 3 4	0 (1) 2 3 4	3
3. Obtaining health care services	0 (1) 2 3 4	0 (1) 2	0 (1) 2 3 4	3
4. Ambulating and moving about	(0) 1 2 3 4	(0) 1 2 3 4	(0) 1 2 3 4	0
5. Learning how to access emergency services	(0) 1 2 3 4	(0) 1 2 3 4	(0) 1 2 3 4	0
6. Maintaining a nutritious diet	(0) 1 2 3 4	(0) 1 2 3 4	(0) 1 2 3 4	0
7. Maintaining physical health and fitness	(0) 1 2 3 4	(0) 1 2 3 4	(0) 1 2 3 4	0
8. Maintaining emotional well-being	(0) 1 2 3 4	(0) 1 2 3 4	(0) 1 2 3 4	0

TOTAL Raw Score Health and Safety Activities: 6

Enter the Raw Score (max. = 94) on the *SIS* Profile, on page 8, Section 1A, Part E, Health and Safety Activities

RATING KEY

FREQUENCY:
How frequently is support needed for this activity?

0 = none or less than monthly
1 = at least once a month, but not once a week
2 = at least once a week, but not once a day
3 = at least once a day, but not once an hour
4 = hourly or more frequently

DAILY SUPPORT TIME:
On a typical day when support in this area is needed, how much time should be devoted?

0 = none
1 = less than 30 minutes
2 = 30 minutes to less than 2 hours
3 = 2 hours to less than 4 hours
4 = 4 hours or more

TYPE OF SUPPORT:
What kind of support should be provided?

0 = none
1 = monitoring
2 = verbal/gestural prompting
3 = partial physical assistance
4 = full physical assistance

4

Supports Intensity Scale, Section 1. ©AAIDD

Section 1. Support Needs Scale, continued

Circle the appropriate number (0–4) for each measurement. (See rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part F: Social Activities	Frequency	Daily Support Time	Type of Support	Raw Scores
1. Socializing within the household	⓪ 1 2 3 ✕	⓪ 1 2 3 4	⓪ 1 2 3 4	0
2. Participating in recreation/leisure activities with others	0 1 ② 3 ✕	0 1 ② 3 4	0 ① 2 3 4	5
3. Socializing outside the household	0 1 ② 3 4	0 1 ② 3 4	0 ① 2 3 4	5
4. Making and keeping friends	⓪ 1 2 3 ✕	0 ① 2 3 4	0 ① 2 3 4	2
5. Communicating with others about personal needs	0 1 ② 3 4	0 1 ② 3 4	0 1 ② 3 4	6
6. Using appropriate social skills	0 ① 2 3 4	0 ① 2 3 4	0 ① 2 3 4	3
7. Engaging in loving and intimate relationships	0 ① 2 3 4	0 ① 2 3 4	0 ① 2 3 4	3
8. Engaging in volunteer work	0 ① 2 3 4	0 ① 2 3 4	0 ① 2 3 4	3
			TOTAL Raw Score Social Activities	27

Enter the Raw Score (max. = 93) on the *SIS* Profile, on page 8, Section 1A, Part F, Social Activities

Section 2. Supplemental Protection and Advocacy Scale

Circle the appropriate number (0–4) for each measurement. (See rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Rank the Raw Scores from highest to lowest (1 = highest). Enter the four highest ranked activities (1–4) and their scores on the *SIS* Profile.

Protection and Advocacy Activities	Frequency	Daily Support Time	Type of Support	Raw Scores	Rank Raw Scores from highest to lowest
1. Advocating for self	0 1 ② 3 ✕	0 1 ② 3 4	0 1 ② 3 4	6	1
2. Managing money and personal finances	0 1 ② 3 4	0 1 ② 3 4	0 1 ② 3 4	6	1
3. Protecting self from exploitation	0 1 ② 3 4	0 1 ② 3 4	0 1 ② 3 4	6	1
4. Exercising legal responsibilities	0 ① 2 3 4	0 ① 2 3 4	0 ① 2 3 4	3	4
5. Belonging to and participating in self-advocacy/support organizations	0 1 ② 3 4	0 1 ② 3 4	0 ① 2 3 4	5	2
6. Obtaining legal services	⓪ 1 2 3 4	0 ① 2 3 4	0 1 ② 3 4	3	4
7. Making choices and decisions	0 1 ② 3 4	0 ① 2 3 4	0 ① 2 3 4	4	3
8. Advocating for others	⓪ 1 2 3 ✕	0 ① 2 3 4	0 ① 2 3 4	2	5

List the four Protection and Advocacy Activities with the highest Raw Score (from highest to lowest) on the *SIS* Profile, on page 8, Section 2.

Supports Intensity Scale, Section 2. ©AAIDD

5

Section 3. Exceptional Medical and Behavioral Support Needs

Circle the appropriate number to indicate how much support is needed for each of the items below. Subtotal the circled 1's and 2's. Total the subtotals. (See rating key.) Complete ALL items.

Section 3A: Medical Supports Needed	No Support Needed	Some Support Needed	Extensive Support Needed
Respiratory care			
1. Inhalation or oxygen therapy	⓪	1	2
2. Postural drainage	⓪	1	2
3. Chest PT	⓪	1	2
4. Suctioning	⓪	1	2
Feeding assistance			
5. Oral stimulation or jaw positioning	⓪	1	2
6. Tube feeding (e.g., nasogastric)	⓪	1	2
7. Parenteral feeding (e.g., IV)	⓪	1	2
Skin care			
8. Turning or positioning	⓪	1	2
9. Dressing of open wound(s)	⓪	1	2
Other exceptional medical care			
10. Protection from infectious diseases due to immune system impairment	⓪	1	2
11. Seizure management	⓪	1	2
12. Dialysis	⓪	1	2
13. Ostomy care	⓪	1	2
14. Lifting and/or transferring	⓪	1	2
15. Therapy services	⓪	1	2
16. Other(s)—Specify: _____	⓪	1	2

	Some Support Needed	Extensive Support Needed
Subtotal of 1's and 2's	O	O
Total (Add Subtotal of 1's and 2's)		O

Enter Total on the *SIS* Profile, on page 8, Section 3A: Support Considerations Based on Exceptional Medical and Behavioral Support Needs, *Medical*

Section 3. Exceptional Medical and Behavioral Support Needs, continued

Circle the appropriate number to indicate how much support is needed for each of the items below. (See rating key.)
Complete ALL items.

Section 3B: Behavioral Supports Needed	No Support Needed	Some Support Needed	Extensive Support Needed
Externally directed destructiveness			
1. Prevention of assaults or injuries to others	(0)	1	2
2. Prevention of property destruction (e.g., fire setting, breaking furniture)	(0)	1	2
3. Prevention of stealing	(0)	1	2
Self-directed destructiveness			
4. Prevention of self-injury	(0)	1	2
5. Prevention of pica (ingestion of inedible substances)	(0)	1	2
6. Prevention of suicide attempts	(0)	1	2
Sexual			
7. Prevention of sexual aggression	(0)	1	2
8. Prevention of nonaggressive but inappropriate behavior (e.g., exposes self in public, exhibitionism, inappropriate touching or gesturing)	(0)	1	2
Other			
9. Prevention of tantrums or emotional outbursts	(0)	1	2
10. Prevention of wandering	(0)	1	2
11. Prevention of substance abuse	(0)	1	2
12. Maintenance of mental health treatments	(0)	1	2
13. Prevention of other serious behavior problem(s) Specify: _____ _____	(0)	1	2

Subtotal of 1's and 2's	*O*	*O*
Total (Add Subtotal of 1's and 2's)		*O*

Enter Total on the *SIS* Profile, on page 8, Section 3B: Support Considerations Based on Exceptional Medical and Behavioral Support Needs, *Behavioral*

RATING KEY

0 = no support needed
1 = some support needed (i.e., providing monitoring and/or occasional assistance)
2 = extensive support needed (i.e., providing regular assistance to manage the medical condition or behavior)

Supports Intensity Scale (SIS) Scoring Form & Profile

99 МиТ 62

ID/TRACKING NUMBER

Name

Darlene Simmons

Date SIS Completed

2003 / 10 / 13 /
YR   MO   DAY

Name of Interviewer

Melissa Anderson

Section 1A: Support Needs Ratings

1. Enter the Raw Scores for parts A–F from pages 2–5.
2. Enter the Standard Scores and Percentiles using Appendix 6.2.
3. Enter the *SIS* Support Needs Index using Appendix 6.3.

Activities Subscales	Total Raw Scores (From pages 2–5)	Standard Scores (See Appendix 6.2)	Subscale Percentiles (See Appendix 6.2)
A. Home Living	26	7	16
B. Community Living	23	5	5
C. Lifelong Learning	28	7	16
D. Employment	15	6	9
E. Health & Safety	6	3	1
F. Social	27	7	16
Standard Scores TOTAL (sum)		35	
SIS **SUPPORT NEEDS INDEX** (Composite Standard Score) (See Appendix 6.3)		71	
Percentile of Support Needs Index (See Appendix 6.3)			3

Section 1B: Support Needs Profile

Circle the Standard Score for each Activities Subscale and the *SIS* Support Needs Index. Then connect the subscale circles to form a graph.

Percentile	A. Home Living	B. Community Living	C. Lifelong Learning	D. Employment	E. Health & Safety	F. Social	*SIS* Support Needs Index	Percentile
99	17–20	17–20	17–20	17–20	17–20	17–20	> 131	**99**
	15–16	15–16	15–16	15–16	15–16	15–16	124–131	
90	14	14	14	14	14	14	120–123	**90**
	13	13	13	13	13	13	116–119	
80							113–115	**80**
	12	12	12	12	12	12	110–112	
70							108–109	**70**
							106–107	
60	11	11	11	11	11	11	105	**60**
							102–104	
50	10	10	10	10	10	10	100–101	**50**
							98–99	
40	9	9	9	9	9	9	97	**40**
							94–96	
30							92–93	**30**
	8	8	8	8	8	8	90–91	
20							88–89	**20**
	(7)	7	(7)	7	7	(7)	85–87	
10	6	6	6	(6)	6	6	82–84	**10**
	5	(5)	5	5	5	5	75–81	
1	1–4	1–4	1–4	1–4	(1–4)	1–4	(< 74)	**1**

Section 2: Support Considerations Based on Protection and Advocacy Scores

List the 4 highest ranked Protection and Advocacy Activities from page 5.

Activity	Raw Score
1. Advocating for Self	6
2. Managing $	6
3. Protection from exploitation	6
4. Participating in Self-Advocacy Organizations	5

Section 3: Support Considerations Based on Exceptional Medical and Behavioral Support Needs

A. MEDICAL

1. Enter the number of Total points from page 6.	0
2. Is this Total larger than 5?	Yes (No)
3. Is at least one "2" circled for Medical Supports Needed on page 6?	Yes (No)

B. BEHAVIORAL

1. Enter the number of Total points from page 7.	0
2. Is this Total larger than 5?	Yes (No)
3. Is at least one "2" circled for Behavioral Supports Needed on page 7?	Yes (No)

If "yes" has been circled on any of the questions above, it is highly likely that this individual has greater support needs than others with a similar *SIS* Support Needs Index.

Comments on Ratings and Scoring for Three Case Studies

These above three case studies present three different people with varying intensities of support need. Each case was drawn from a real individual (names and identifying information were changed). Together they illustrate how differences exist among individuals within the mental retardation-developmental disabilities service system in regard to how frequently a support might be needed, the amount of time the support needs to be in place on a typical day when it is provided, and the different types of support that might be required.

The first case study (Darlene Simmons) presents a woman who has relatively few support needs. Her *SIS* Support Needs Index was 71, which places her in the 3rd percentile; that is, 3% out of 100 individuals in the standardization sample had less intensive support needs than she. According to the background information in the case study, she works regularly and lives with a roommate in her own apartment. Ms. Simmons receives many of her supports from natural sources (i.e., family, friends) and requires little paid staff support. Despite receiving many supports from family or other natural supports, it is important to rate the frequency, daily support time, and type of support, because they are needed. The *SIS* measures all types and forms of needed supports. Who provides those supports should be determined by the individual and the significant others in their lives.

The second and third case studies present people with more intense support needs but for different reasons. Both case studies illustrate how the *SIS* Support Needs Index can underestimate the support needs of individuals due to exceptional medical and/or behavioral issues. The case studies revealed that the Index provided a relative support need level in 50th percentile and 47th percentile for Mr. Garcia and Mr. Thurber respectively. However, in both cases the intensity of support needs was underestimated due to medical (in Mr. Garcia's case) and behavioral (in Mr. Thurber's case) issues. It is important to draw attention to Section 3 on the *SIS* Profile Scoring Form in these two case studies: Please note that on both cases two "yes" responses were checked, indicating that the *SIS* Support Needs Index was likely underestimating their support needs.

In the second case study, Mr. Garcia has physical disabilities and health issues that necessitate full physical assistance to complete many activities. Please note, when another person is needed to complete a function or task in place of the individual, this should be rated as "full physical assistance" (TS = 4). Mr. Garcia lives at home with his family and, like Ms. Simmons, receives a fair amount of his support from natural sources. Nonetheless, he has exceptional support needs in several areas.

Mr. Thurber is the focus of the third case study. He is a person with a mild cognitive disability and relatively good adaptive behavior skills. However, due to the presence of significant mental health and behavioral problems, he requires one-on-one supervision at all times. Despite being a fairly capable man, Mr. Thurber requires intense supports due to his exceptional behavioral support needs.

Additional Scoring Examples

The three cases, above, offer the opportunity to discuss some ratings that may not be self-evident. Here we present additional brief examples of different levels of support need and types of support and how they should be coded on the *SIS*.

Example 1: More Than One Rating

A person might require multiple types of support to complete an activity successfully. Only one rating should be entered for *each* of the three dimensions (frequency, daily support time, and type of support). The *highest* rating of the different types of support needed should be recorded in the case where multiple supports are needed. For example, in Part F (Social Activities), Item 2 (participating in recreation/leisure activities with others), Ms. Simmons might need both monitoring (rated 1) and verbal/gestural prompting (rated 2) as types of support. A rating of "2" would be entered by the interviewer in this case.

Example 2: Needing to Be Transported

There are people with developmental disabilities who have drivers' licenses and own their own cars or have access to friends' cars. Others may use public transportation. Some people with developmental disabilities may not be able to drive or have access to public transportation. Thus they rely on family, friends, or paid staff to transport them. For these people, for Part B (Community Living Activities) Item 4 (going to visit friends and family), the type of support entered would be full physical assistance (rated 4), because they need someone to physically assist them. Transportation is essential to successfully completing in this particular activity.

Example 3: Assistive Technology

All items should be completed based on an individual's typical functioning. If the individual typically functions with assistive technology, he or she should be rated based on his or her functioning while using the technology. For example, Part D (Employment Activities) Item 3 is "interacting with co-workers." If an individual uses an augmentative communication device to expressively communicate with his or her co-workers in a largely independent and fluid manner, such an individual may actually need low frequency (F = 1, for monthly), negligible daily time (DST = 1, for < 30 minutes), and low type (TS = 1, for monitoring) of support and should be rated as such.

Conclusion

This chapter described how to score the three sections of the *SIS* and gave instructions on how to compute the support need ratings (i.e., the subscale ratings and the *SIS* Support Needs Index). The chapter provided information on two significant differences between the profile and intensity of needed supports obtained through the *SIS* and the four support

intensity levels (intermittent, limited, extensive, pervasive) discussed in the Luckasson et al. 1992 and 2002 AAIDD manuals: *Mental Retardation: Diagnosis, Classification, and Systems of Supports.* We also discussed the potential use of *SIS* data to group or classify individuals by the intensity of needed supports. Specifically, three potential techniques were outlined. The chapter concluded with three case studies to illustrate how the *SIS* is scored and the types of information that can be gathered using the scale.

Using the *SIS* to Develop Individualized, Person-Centered Support Plans

S upport providers, parents, family members, and people with an intellectual disability can use the results from the *Supports Intensity Scale (SIS)* to make decisions about the types and intensities of supports needed. Such decisions are best made within the context of a systematic planning and monitoring process that actively involves the person with the disability, his or her family members, and other key stakeholders.

Figure 4.1 shows a four-component planning process: (a) identifying a person's desired life experiences and goals, (b) determining the pattern and intensity of an
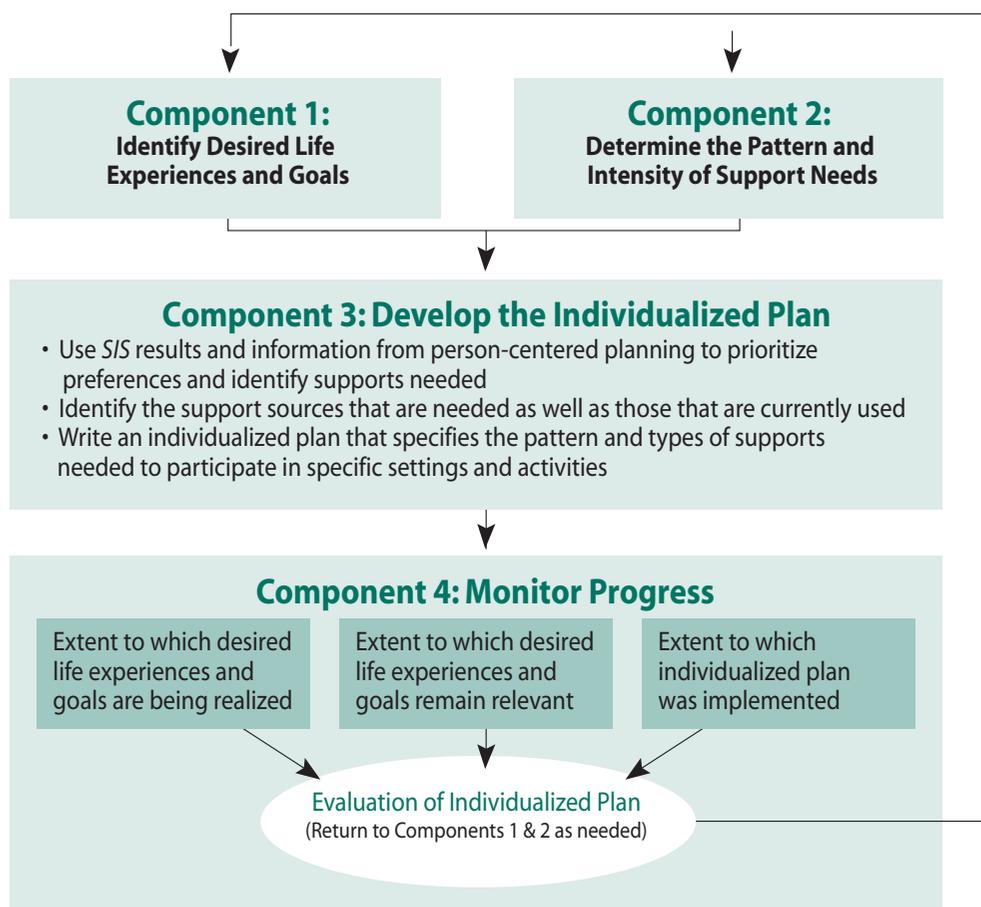
Figure 4.1. Four-component support needs assessment, planning, and monitoring process.

Adapted from "Integrating Supports in Assessment and Planning," by J. R. Thompson, C. Hughes, R. L. Schalock, W. Silverman, M. J. Tassé, B. Bryant, et al., 2002, *Mental Retardation 40,* p. 391. Copyright 2002 by American Association on Mental Retardation. Adapted with permission of American Association on Mental Retardation.

individual's support needs, (c) developing an individualized support plan, and (d) monitoring the progress of the plan (adapted from Thompson, Hughes, et al., 2002, pp. 390–405). In this chapter each of these components is described, and the case studies introduced in chapter 3 are expanded to further illustrate implementation of this planning process.

A Support Needs Assessment, Planning, and Monitoring Process

Component 1: Identify Desired Life Experiences and Goals

Component 1 involves identifying priority areas to be addressed when developing a personalized support plan. *This requires a person-centered planning process* (e.g., Holburn & Vietze, 2002). Using a person-centered approach to identify desirable life experiences and goals ensures: (a) respect for the individual *to assure that he or she remains in control of the process,* (b) participation of a team of friends and supporters that recognizes the dreams and goals of the individual, (c) a role for people in addition to professionals and a primary emphasis on community resources, and (d) the creation of and strategies for achieving life experiences desired by the person being supported.

It is essential that a person's current daily activities and environments be compared with what the person prefers or considers desirable, everyday experiences and situations. Informally interviewing the person and his or her family and advocates can help identify (a) priority areas in which the person desires lifestyle changes and (b) current activities the person would like to maintain. In addition, interviews can identify supports needed to maintain or change priority activities as desired. During the interview process, be careful to ensure that cultural, ethnic, linguistic, and economic backgrounds of informants are respected and that accommodations, such as interpreters or graphic organizers, are used as needed to facilitate full participation (Marrone, Hoff, & Helm, 1997).

Component 2: Determine the Pattern and Intensity of Support Needs

Component 2 of the planning process involves assessing a person's support needs using a psychometrically sound support needs scale. Information from the *SIS* can be used *in conjunction with person-centered planning* to guide a team to develop an individualized plan to achieve the person's desired goals. The Support Needs Profile (Figure 3.3) is particularly useful to inform and guide a planning team to identify supports that should be introduced, maintained, or discontinued for an individual to achieve a culturally valued lifestyle. Informal assessments, such as direct observation and anecdotal logs, can be used in conjunction with the *SIS* and person-centered planning to identify support needs.

Component 3: Develop the Individualized Plan

A planning team needs to combine information from Component 1 (prioritize preferences in terms of life experiences and goals) and Component 2 (determine the pattern and intensity of support needs) to develop an individualized plan, which can be called an

individualized program plan, individualized support plan, individualized habilitation plan, or any other similar name. An individualized plan is completed when the team has identified: (a) the individual's interests and preferences, (b) the needed support areas and activities, (c) the settings the person is most likely to be in as well as the activities in which the individual will participate, (d) the specific support functions that will address the identified support needs, (e) natural supports available to the person, (f) valued personal outcomes, and (g) a mechanism to monitor the provision and effectiveness of the support provided. The result should be an unambiguous, individualized plan that specifies (a) the settings for and activities in which a person is likely to engage during a typical week, and (b) the types and intensities of support that will be provided (and by whom). Later in this chapter, we present sample individualized support plans for the case studies introduced in chapter 3.

Component 4: Monitor Progress

For the planning team, Component 4 involves comparing the actual outcomes of the support planning process to the desired outcomes identified by the individual and his or her team. Further, expected supports received/not received are evaluated. Planning teams can then identify barriers to implementation and achievement of anticipated outcomes and introduce strategies to promote desired lifestyle changes. A responsive process is characterized by regular communication among planning-team members regarding potential changes to a plan based upon the changing needs and circumstances of the individual.

Three Examples of Individualized Supports Planning

Individualized Support Plan for Darlene Simmons

Name: Darlene Simmons

Age: 35 years

Date: 10/19/03

Current Daily Activities and Environments:

Ms. Simmons currently works 20 hours per week at Hillwood Hardware in the billing department. She rides the city bus to work from her supported-living apartment where she lives with her roommate. Ms. Simmons and her roommate receive weekly assistance from family members and from Jackie Delmonte at Outlook, Inc., in home living and financial management activities. Ms. Simmons likes to socialize with family members several times a week at family homes. She also is involved in recreational, educational, and social activities in her local community center.

Interests, Preferences, and Desired Outcomes:

Ms. Simmons indicates that although she likes working at Hillwood Hardware, she is becoming dissatisfied with the monotony of her job. She would prefer to work more directly with customers where she could use her "people skills," perhaps at the cash register or helping customers find items on the shelves. Ms. Simmons also is concerned that she has seen little increase in her paycheck over

the past year and would like to speak to her supervisor about a raise, as she needs additional funds for a cooking class she would like to take at the community center.

Ms. Simmons says that she is "very happy" with her supported-living apartment and her roommate and doesn't want any changes with her living situation. She does, however, state that she's frustrated because she can't cook complete meals, and she feels this is keeping her from entertaining family and friends. She would like to learn to cook some of the meals she's seen on the Cooking Channel on television and wants some assistance in learning how to cook and purchase some cooking utensils.

Although Ms. Simmons indicates that she has a full social life and that she likes the "special rec." activities at the community center, she feels she wants to "branch out" to other groups and activities. She would like to audition for one of the plays that's being put on at the Sunset Theater, but she says she has been too afraid to try out.

As far as her general health is concerned, Ms. Simmons feels healthy and that she is taking good care of herself. However, she is upset that she has to wear glasses with such thick lenses; she feels it's affecting her appearance and what people think of her. She says she would like help getting contact lenses and learning how to wear them.

Needed Supports:

Ms. Simmons met with her support team to identify areas needing support as identified in the *SIS*. Analysis of Ms. Simmons' *SIS* scores revealed that she needed support advocating for herself, managing her money and personal finances, and protecting herself from exploitation. Several items in the Home Living Activities subscale, particularly preparing food, laundering clothes, and housekeeping, were also identified on the *SIS*. Finally, although Ms. Simmons' scores on the Health and Safety Activities indicated low support needs, the team determined that Ms. Simmons' support needs in the area of protection and advocacy hindered her from taking the necessary steps to pursue her desire to switch from wearing eyeglasses to wearing contact lenses. Consequently, based on *SIS* results and input from Ms. Simmons and her support team, the following areas of support need were identified:

1. Helping Ms. Simmons to speak up and advocate for herself, such as at work when asking for a change in job tasks or a pay raise or in the community when she wants to try out new activities and meet new people outside her special rec. options.

2. Helping Ms. Simmons enroll in a cooking class, purchase cooking utensils, and learn to use her cooking skills to entertain at home.

3. Helping Ms. Simmons make an appointment to see an eye doctor to get fitted for contact lenses and to help her learn to insert and wear them correctly.

Specific Support Functions and Natural Supports Available to Address Support Needs:

1. At the community center Ms. Simmons is currently taking a class to learn to say no to unsafe or inappropriate demands. An additional focus of the class should be to help Ms. Simmons advocate for herself in different situations both in role-play and in the natural environment. Jackie Delmonte will speak with staff at the community center to expand the curriculum of the class to address this need. Family members will provide opportunities for Ms. Simmons to advocate for herself in the community. Ms. Simmons' aunt, who also works at Hillwood Hardware, will check on Ms. Simmons' progress in advocating for a job change and pay raise at work.

2. Ms. Simmons' sister, Raelynn Foster, is also interested in learning to cook and will enroll together with Ms. Simmons in a cooking class at the community center. Together, they will shop for cooking utensils and plan future entertainment events at Ms. Simmons' apartment when they feel comfortable with their cooking skills.

3. Ms. Simmons' mother will arrange for a doctor's appointment for Ms. Simmons to be fitted with contact lenses, and Jackie Delmonte will assist with the paperwork to ensure medical coverage. Ms. Simmons' roommate, Vicky Elliston, who already wears contact lenses, will help Ms. Simmons adhere to her wearing schedule and care routine and will provide emotional support to Ms. Simmons as she adjusts to her new lenses.

Progress Evaluation Plan:

Jackie Delmonte and Ms. Simmons' mother and aunt will monitor Ms. Simmons' progress in advocating for herself at work and in the community. In addition, Mr. Delmonte will communicate with staff at the community center to determine Ms. Simmons' progress in classes. Ms. Foster will monitor Ms. Simmons' progress in learning to cook and entertain at home. Mr. Delmonte will communicate with Ms. Simmons' eye doctor and roommate to check on Ms. Simmons' progress in adapting to and caring for her contact lenses. Mr. Delmonte and all family members providing support will check at least weekly with Ms. Simmons to determine her level of satisfaction with attaining her valued outcomes.

Individualized Support Plan for Juan Garcia

Name: Juan Garcia

Age: 21 years

Date: 12/01/03

Current Daily Activities and Environments:

Mr. Garcia currently attends classes 6 hours daily at the Hidalgo Academy. He is transported to and from school by a school district special transportation van. He is in a self-contained special-education classroom that primarily serves youth with physical disabilities. He lives with his mother and two younger siblings. Outside of school, most of his activities are with his immediate family and relatives in the area. Because of his respiratory infections, activities outside the home are limited.

Interests, Preferences, and Desired Outcomes:

Mr. Garcia communicates that he is happy living with his family and wants to continue to do so. The other family members are supportive of his remaining at home. Mr. Garcia also communicates that he wants to continue learning things and to spend time with his friends.

Mr. Garcia's mother reports that he is receiving a variety of special therapies through the school and has some concerns about their continuation after his graduation. She wants him to be healthy and to make as much progress as possible. In addition, she would like to be able to take him places more easily.

Needed Supports:

At the planning team meeting the service coordinator, Dan Post, summarized the findings of the *SIS* assessment. Full physical assistance is required for all Home Living and Community Living Activities. Further, much of this support is required at least daily for periods up to an hour. Support require-