

**RESULTS OF SURVEYMONKEY REGARDING AUTISM SPECTRUM
DISORDERS 10/19/07 – 11/3/07**

1. Vermont County of Residence:

County	Response Percent	Response Count
Addison	6.0%	30
Bennington	3.0%	15
Caledonia	3.0%	15
Chittenden	22.1%	111
Essex	1.4%	7
Franklin	8.2%	41
Grand Isle	1.6%	8
Lamoille	2.2%	11
Orange	2.4%	12
Orleans	2.4%	12
Rutland	14.7%	74
Washington	12.5%	63
Windham	3.0%	15
Windsor	17.7%	89

**Answered question 503
Skipped question 0**

2. My role:

Parent	20.7%	104
Individual with ASD	0.4%	2*
Professional	81.1%	408

*Due to the low number of individuals with ASD responding, the results would not be representative of individuals with ASD and therefore will not be reported here.

**Answered question 503
Skipped question 0**

RESPONSES FROM PARENTS (QUESTIONS 3-19)

3. The current age of my child/family member with ASD: (105 answered question)

Age range	Response Percent	Response Count
2 – 5	20.0%	22
6 – 16	55.0%	60
17 – 22	16.0%	18
23 – 48	9.0%	10

4 & 5. Age when family member was diagnosed and diagnosis: (105 answered question, including 2 families with more than one child with ASD)

Age Ranges	Autistic Disorder	PDD-NOS
1.5 – 2.11	15	5
3.0 – 3.11	15	6
4.0 – 4.11	4	4
5.0 – 5.11	8	2
6.0 – 6.11	4	1
7.0 – 9.11	2	8
10.0 – 23.0	5	5
Total	53	31

Age Ranges	Asperger's Disorder
3.0 – 6.11	7
7.0 – 11.11	8
13.0 – 15.11	6
19.0 – 36.0	2
Total	23

7. Is your family member working? Only 9% of the total survey respondents are above school age (see Number 3)

	Response Percent	Response Count
Yes, with supports	6.8%	7
Yes, on his/her own with no supports	3.9%	4
No	72.8%	75
Other (still a student)	16.5%	17

8. How are services funded for your family member? (101 answered question)

Funding Source	Response Percent	Response Count
Medicaid/Katie Beckett waiver	45.5%	46
Medicaid/Dr. Dinosaur	25.7%	26
Medicaid	12.9%	13
CSHN -Children with Special Health Needs	22.8%	23
Private Insurance	32.7%	33
Grants	8.9%	9
Private sector funding	0.0%	0
Medicare	2.0%	2
Supplemental Security Income (SSI)	30.7%	31
Flexible Family Funding	28.7%	29
Developmental Services (Home and community-based waiver, other)	13.9%	14
Personal Care Services	45.5%	46
Children's Mental Health	2.0%	2
Adult Mental Health	1.0%	1
Family, Infant and Toddler Program	4.0%	4
Education/school district	46.5%	47
Vocational Rehabilitation	3.0%	3
Out of Pocket *	39.6	40

* Of 7 people who provided an amount, responses included a range of \$600.00 to over \$10,000.00 per year in out of pocket expenses.

9. Rate the level of training of the following individuals who work with your family member on the autism spectrum. (101 answered question)

Providers	High Level training	Some training	Inadequate training	Count
Personal Care Attendants	15.7% (11)	50.0% (35)	34.3% (24)	70
Respite Workers	3.2% (1)	54.8% (17)	41.9% (13)	31
Special Educators	35.6% (31)	39.1% (34)	25.3% (22)	87
General Educators	9.8% (8)	30.5% (25)	59.8% (49)	82
School Administrators	12.9% (11)	35.3% (30)	51.8% (44)	85
Occupational Therapists	39.1% (27)	43.5% (30)	17.4% (12)	69
Physical Therapists	36.2% (17)	46.8% (22)	17.0% (8)	47
Speech/Language Pathologists	48.6% (35)	33.3% (24)	18.1% (13)	72
Primary Care Physicians	20.7% (19)	38.0% (35)	41.3% (38)	92
Dentists	15.3% (13)	38.8% (33)	45.9% (39)	85
School Case Managers	28.4% (21)	33.8% (25)	37.8% (28)	74
Agency Case Managers	23.7% (9)	42.1% (16)	34.2% (13)	38
Vocational Rehabilitation				
Counselors	0.0% (0)	33.3% (3)	66.7% (6)	9
Job Coaches	0.0% (0)	30.0% (3)	70.0% (7)	10
Developmental Educators				
(FITP)	27.2% (3)	36.4% (4)	36.4% (4)	11
Para-educators	9.7% (7)	41.7% (30)	48.6% (35)	72
Counselors	18.2% (6)	45.5% (15)	36.3% (12)	33
Mental Health Workers	16.7% (4)	45.8% (11)	37.5% (9)	24
Developmental Services Staff	9.1% (2)	36.4% (8)	54.5% (12)	22
Foster Care Providers	66.7% (2)	0.0% (0)	33.3% (1)	3
Developmental Home Providers	0.0% (0)	42.9% (3)	57.1% (4)	7
Daycare Providers	15.4% (4)	11.5% (3)	73.1% (19)	26
Behavior Specialists	37.2% (16)	48.8% (21)	14.0% (6)	43

See additional comments at the end of this report.

10. What services are you currently accessing? (99 answered question)

Services	Frequently enough or addressing the need	Not frequently enough or not addressing the need*	Count
Occupational Therapy	36% (27)	64% (48)	75
Physical Therapy	37.1% (23)	62.9% (39)	62
Speech and Language	41.3% (33)	58.7% (47)	80
Behavior Support	36.5% (27)	63.5% (47)	74
Special Education –IEP	51.2% (42)	48.8% (40)	82
504 Plan	3.3% (1)	96.7% (29)	30
Personal care	63.4% (45)	36.6% (26)	71
Respite	28.1% (16)	71.9% (41)	57
Mental Health	28.6% (14)	71.4% (35)	49
Case Management outside of school	28.1% (16)	71.9% (41)	57
Transition services	7.7% (3)	92.3% (36)	39
Children with Special Health Needs –CSHN	37.5% (18)	62.5% (30)	48
Family, Infant & Toddler Program FITP	13.8% (4)	86.2% (25)	29
Interagency/Coordinated Services Plan/Act 264	0.0% (0)	100.0% (33)	33
Adaptive Recreation	15.6% (7)	84.4% (38)	45
Education Support Team (EST)/Act 157 Plan	15.2% (5)	84.8% (28)	33
Parent training	33.8% (23)	66.2% (45)	68
Parent Support	44.0% (29)	56.0% (37)	66
Employment services/ job coaches	9.8% (4)	90.2% (37)	41
Elder care	0.0% (0)	100.0% (25)	25
Functional life skills	32.0% (16)	68.0% (34)	50
Social Skills training	27.7% (18)	72.3% (47)	65

Vocational rehabilitation			
counseling	8.3% (3)	91.7% (33)	36
Developmental services	27.8% (15)	72.2% (39)	54
Counseling	20.9% (9)	79.1% (34)	43

*Based upon the response profile, a portion of responses appear to reflect the lack of availability of services rather than dissatisfaction of people who are currently receiving a service.

See additional comments at the end of this report.

11. What services do you need, but DON'T currently have access to? Number the top three services needed. (85 answered question)

Services	Response Percent	Response Count
	(% who rated as one of top 3 choices)	(# who rated as one of top 3 choices)
Social skills training	69.4%	59
Functional Life skills	49.4%	42
Behavior Support	37.7%	32
Parent training	33.0%	28
Adaptive Recreation	23.5%	20
Case Management out of school	20.0%	17
Respite	16.5%	14
Parent support	15.3%	13
Occupational Therapy	13.0%	11
Speech and Language	11.8%	10
Counseling	10.6%	9
Personal Care	9.4%	8
Developmental services	7.1%	6
Interagency Coordinated services		
Plan/Act 264	7.1%	6
Employment services/job coaches	5.9%	5
Transition Services	5.9%	5
Physical Therapy	5.9%	5

Special Education – IEP	5.9%	5
Mental Health	4.7%	4
Vocational rehabilitation counseling	3.5%	3
504 Plan	2.4%	2
Children with Special Health Needs	2.4%	2
Education Support Team/Act 157	0.0%	0
Elder care	0.0%	0
Family, Infant & Toddler	0.0%	0

12. How has supporting an individual with an autism spectrum disorder impacted your family? (98 answered question)

	Response Percent	Response Count
Stress	100.0%	98
Depression	57.1%	56
Job loss	34.7%	34
Economic	61.2%	60
Social isolation	61.2%	60
Marital difficulties	52.0%	51
Sibling issues	51.0%	50
Extended family relationships	37.8%	37

See additional comments at the end of this report.

13. Where is your child receiving his/her education? (94 answered question)

	Response Percent	Response Count
Home schooled	4.3%	4
Home tutoring	2.1%	2
Hospital	0.0%	0
Regular school environment	54.3%	51
Resource for some part of the day	18.1%	17
Separate classroom within the regular environment	17.0%	16

Alternative school program within the school district	10.6%	10
Alternative school program outside the school district	3.2%	3
Residential school (in or out of state)	3.2%	3
Independent school	2.1%	2
Day care	2.1%	2
College	6.4%	6
Vocational technical school	1.1%	1

See additional comments at the end of this report.

14. What are the interventions/treatment modalities that have been effective in working with your family member with ASD? (91 answered question)

	Response Percent	Response Count
Visual supports	60.4%	55
Positive Behavior Supports	55.0%	50
Sensory Integration	53.9%	49
Social Stories	49.5%	45
Applied Behavior Analysis -ABA	45.1%	41
Social Skills	42.9%	39
Picture Exchange Communication System -PECS	37.4%	34
Discrete Trial Learning/Training	35.2%	32
Floortime/DIR	34.1%	31
Relationship Development Intervention -RDI	18.7%	17
Nutrition/Diet	18.7%	17
Counseling	18.7%	17
Verbal Behavior	17.6%	16
Augmentative and Alternative Communication	15.4%	14
Video Modeling	15.4%	14

TEACCH	13.2%	12
Peer-mediated interventions	13.2%	12
Bio-Medical	11.0%	10
Cognitive Behavioral Therapy	8.8%	8
Facilitated Communication -FC	7.7%	7
Pivotal Response Training	3.3%	3
SonRise	1.1%	1
Dialectic Behavioral Therapy -DBT	1.1%	1
SCERTS	0.0%	0

See additional comments at the end of this report.

15. Where does your family member with ASD live? (96 answered question)

	Response Percent	Response Count
Home/apartment with family	90.6%	87
Home/apartment with support	3.1%	3
Home/apartment with roommate	3.1%	3
Home/apartment with no support	1.0%	1
Home/apartment with spouse/partner	1.0%	1
Homeless	0.0%	0
Developmental Home	2.1%	2

Other:

Apartment built on house for adult with ASD to gain some independence

Living at a residential school in “house” with other students

Living in college dorm

16. What are barriers to appropriate living arrangements for adults? (48 answered question)

	Response Percent	Response Count
Lack of funding	79.2%	38
Lack of support available in family home	56.3%	27
Lack of supported homes available	54.2%	26

Additional comments:

- apartments with manager who is available and aware of ASD
- no options other than staying with family or moving into a developmental home
- no support available for people who are not eligible for developmental services
- no group homes
- companion-type living arrangements are needed
- when people with autism reach a certain age they are no longer important
- services are not available to individuals who are too high functioning

17. Do you have suggestions for the preparation of individuals with ASD for living independently?

52 people responded

Comments include:

- Intensive program taught by experienced professionals with training in ASD
- Parents as valuable members of the educational team
- Early intervention and modeling
- Strong transition plans
- Collaboration between school and home-based programming
- Better funding to schools
- More funding to train and work with people
- More community support post high school
- Day programs with planned activities

- More social opportunities with other disabled adults
- Include independent living skills
- Self-help skills and self confidence
- Social and functional life skills (cooking, cleaning, bathing, bill paying, budgeting, use of leisure time, job coaching, relationships, etc.)
- More apartment programs (practice apartment programs)
- More supported housing options
- TEACCH
- PECS
- Group homes
- Apartments with “active manager” for consulting and safety
- More flexibility for parents to choose programs and schooling
- Centers to address the specific needs of the autism community
- Stop thinking grade K-12 and begin teaching 0-90 years of age

See additional comments at the end of this report.

18. What supports have been most effective for you and your family?

70 people responded

Responses include:

- ABA
- DTL; trained interventionists
- RDI
- TEACCH
- Floortime
- Trained professionals
- SLP
- OT/PT
- Sensory integration
- PCA and IA
- Caring paraeducators

- Career Choices program through Community Access Program
- Augmentative Movement and Learning Center
- Autism collaboratives
- Vermont Parent Information Center
- Parent to Parent
- Elementary School
- Family centered school
- Multidisciplinary IEP team
- Special educators
- Respite/time away
- Therapist (family therapy)
- Medication
- UCS counseling
- Consultants to school programming
- FITP team
- Unified team
- Financial supports
- Flexible family funding
- Professionals trained in direct instruction
- visual supports
- home-based case manager with experience with adult services
- trainings
- other families
- social skills

See additional comments at the end of this report.

19. What supports have been least effective for you and your family?

56 people responded

Responses include:

- lack of available school program/learning environment

- school district, fighting for services
- untrained school personnel
- absence of options
- after school care
- lack of recreational programs
- adaptive sports programs
- not enough PCA hours
- professionals who do not understand the disability
- lack of funding
- endless paperwork
- not listening to parents
- fragmented services
- lacked of coordination between school services and purchased services
- services not integrated throughout the day
- not eligible for IEP due to grade level performance
- no services available for home school students
- summer school services
- non adherence to FAPE
- good intended but untrained supportive staff
- not enough physicians
- voc rehab and adult services

See additional comments at the end of this report.

(Questions 20-30 were for individuals with ASD and are not reported here as there were only two respondents.)

RESPONSES FROM PROFESSIONALS (QUESTIONS 31-38)

31. Ages of individuals I work with:

Ages	Response Percent	Response Count
0 -3	32.3%	129
3 -5	54.8%	219
6 -16	64.5%	258
16 - 22	42.5%	170
22 - 30	15.3%	61
30 - up	13.0%	52

answered question 400

skipped question 102

32. Individuals with ASD in your program have access to the following professionals with the following level of training:

	High Level of training	some training	Inadequate training	Response Count
Personal Care Attendants	11.4% (29)	62.2% (158)	26.4% (67)	254
Respite workers	6.6% (13)	59.4% (117)	34.0% (67)	197
Special Educators	55.8% (191)	39.5% (135)	4.7% (16)	342
General Educators	22.0% (70)	48.7% (155)	29.3% (93)	318
Schools Administrators	23.9% (74)	51.1% (158)	24.9% (77)	309
Occupational Therapists	68.2% (217)	29.6% (94)	2.2% (7)	318
Physical Therapists	60.8% (175)	36.1% (104)	3.1% (9)	288
Speech-Language Paths.	65.1% (211)	29.9 (97)	4.9% (16)	324
Primary Care Physicians	30.3% (66)	48.6% (106)	27.1% (81)	218
Dentists	23.4% (33)	31.2% (44)	45.4% (64)	141
School Case Managers	41.7% (126)	53.0% (160)	5.3% (16)	302
Agency Case Managers	39.3% (84)	47.7% (102)	13.0% (28)	214
Voc Rehab Counselors	33.6% (43)	39.1% (50)	27.3% (35)	128
Job Coaches	21.2% (25)	53.4% (63)	25.4% (30)	118
Para-educators	14.8% (36)	57.6% (140)	27.6% (67)	243

Counselors	28.6% (66)	54.5% (126)	16.9% (39)	231
Mental Health workers	31.1% (66)	50.5% (107)	18.4% (86)	212
Developmental services staff	32.0% (54)	55.0% (93)	13.0% (22)	169
Foster care providers	8.2% (8)	49.5% (48)	42.3% (41)	97
Developmental home prov.	14.3% (14)	61.2% (60)	24.5% (24)	98
Daycare providers	5.2% (8)	27.9% (43)	66.9% (103)	154
Behavior specialists	59.4% (151)	33.5% (85)	7.1% (18)	254

33. What are the interventions/treatments modalities that have been effective in your work with individuals with ASD?

Intervention	Response percent	Response Count
Visual supports	72.4%	260
Social skills	70.2%	252
Social stories	68.0%	244
Positive Behavior supports	67.7%	243
Picture Exchange Communication System -PECS	67.4%	242
Sensory Integration	65.2%	234
Applied Behavior Analysis -ABA	58.2%	209
Augmentative and Alternative Communication	53.8%	193
Discrete Trail Learning/Teaching	51.0%	183
Floortime/DIR	41.8%	150
TEACCH	39.0%	140
Relationship Development Intervention -RDI	27.6%	99
Verbal Behavior	25.9%	93
Counseling	24.2%	87
Peer-mediated interventions	22.8%	82
Cognitive behavioral therapy	21.2%	76
Video modeling	20.6%	74
Nutrition/Diet	19.5%	70
Facilitated Communication -FC	18.9%	68
SCERTS	11.4%	41

Bio-medical	8.1%	29
Pivotal response training	7.0%	25
Dialectic Behavioral Therapy -DBT	6.4%	23
SonRise	0.3%	1

See additional comments at the end of this report. 58

answered question 359

skipped question 143

34. Please rate your level of qualification/extent of familiarity with each of the following: RATE:

1=no training or familiarity;

2=some familiarity, minimal training, may use some methods

3= moderate level of training or familiarity, comfortable using methods

4 = have highest level of training; frequently use the methods

	1	2	3	4	# responses
Characteristics of Autism Spectrum Disorders	4.6% (18)	24.3% (95)	44.5% (174)	26.6% (104)	391
TEACCH/Structured Teaching	39.8% (151)	32.2% (122)	24.8% (94)	3.2% (12)	379
Discrete Trial Training	30.7% (117)	31.0% (118)	29.4% (112)	8.9% (34)	381
Applied Behavior Analysis	22.4% (85)	33.8% (128)	30.1% (114)	13.7% (52)	379
Cognitive Behavioral Therapy	35.9% (132)	36.4% (134)	20.7% (76)	7.1% (26)	368
Assistive Technology	23.1% (86)	38.2% (142)	31.7% (118)	7.0% (26)	372
AAC	54.3% (190)	20.9% (73)	16.0% (56)	8.9% (31)	350
PECS	36.4% (137)	24.2% (91)	25.8% (97)	13.6% (51)	376

SCERTS	68.2% (234)	22.2% (76)	6.4% (22)	3.2% (11)	343
RDI	59.3% (208)	25.4% (89)	12.8% (45)	2.6% (9)	351
Verbal Behavior	47.4% (164)	31.8% (110)	15.9% (55)	4.9% (17)	346
Video Modeling	53.2% (185)	31.9% (111)	10.3% (36)	4.6% (16)	348
Floortime/DIR	38.6% (140)	33.6% (122)	21.2% (77)	6.6% (24)	363
Social Stories/Comic Strip Conversations	21.1% (80)	26.9% (102)	36.4% (138)	15.6% (59)	379
Visual Supports	20.2% (76)	26.3% (99)	31.1% (117)	22.3% (84)	376
Pivotal Response Training	72.2% (249)	16.5% (57)	8.1% (28)	3.2% (11)	345
Peer Mediated Interventions	48.5% (172)	28.7% (102)	16.9% (60)	5.9% (21)	355
Sensory Integration	19.3% (71)	35.3% (130)	34.2% (126)	11.1% (41)	368
Positive Behavior Supports	17.5% (58)	32.0% (106)	30.2% (100)	20.2% (67)	331
See additional comments at the end of this report					29
Answered question					394
Skipped question					108

35. What do you think would be effective in increasing the number of trained professional working with persons with ASD in Vermont? Please rate the following: 1 = not effective 2 = somewhat effective 3 = very effective

	1	2	3	Response Count
More time for staff development within the work setting	2.0% (8)	27.6% (108)	70.3% (275)	391
Courses/training available closer to you	2.8% (11)	36.3% (142)	60.9% (238)	391
Courses/training available more often	3.9% (15)	36.7% (142)	59.4% (230)	387
Mentorship - On-site training/consultation from a person able to train in a specific program/method	3.4% (13)	22.7% (88)	74.0% (287)	388
A manageable workload for case management and direct service	2.1% (8)	23.4% (91)	74.6% (290)	389
Competitive salary and benefits	6.0% (23)	23.4% (89)	70.6% (269)	381
Opportunities to collaborate with other trained professionals	1.0% (4)	23.0% (90)	76.0% (298)	392
Less time spent with paperwork/legal obligations, more time available for students/supervision	2.6% (10)	29.7% (115)	67.7% (262)	387
Web tools to provide more off-site consultation	13.7% (53)	53.7% (208)	32.6% (126)	387
Continued professional development opportunities for training at an advanced level	2.9% (11)	28.2% (108)	68.9% (264)	383
See additional comments at the end of this report				47

	<i>answered question</i>	396
	<i>skipped question</i>	106

36. What methods would be most effective for establishing trained professional to work with individuals with ASD? Rate: 1 = not effective 2 = somewhat effective 3 = very effective					
	1	2	3	Rating Average	Response Count
Provide a certification and/or licensure program through higher education in ASD	10.5% (41)	40.5% (158)	49.0% (191)	2.38	390
Provide a course of study through higher education in ASD	3.6% (14)	44.9% (175)	51.5% (201)	2.48	390
Provide a mentoring program with experts in ASD coaching targeted professionals	2.1% (8)	25.7% (100)	72.2% (281)	2.70	389
Use of distance web tools for certification programs, courses of study, mentorships	15.6% (61)	57.7% (226)	26.8% (105)	2.11	392
Create regional teams with specific expertise in ASD	6.5% (25)	34.3% (132)	59.2% (228)	2.53	385
Create trainer models with individuals with expertise in ASD training local professionals	4.1% (16)	32.5% (126)	63.4% (246)	2.59	388
Cross-training opportunities for collaboration with other disciplines	3.9% (15)	38.0% (145)	58.1% (222)	2.54	382
See additional comments at the end of this report					31
	<i>answered question</i>				395

	skipped question	107

37. What are barriers to appropriate living arrangements for adults with ASD?

	Percent Response	Response Count
Lack of funding	81.9%	249
Lack of support available in the family home	71.4%	217
Lack of supported living arrangements	78.2%	265
See comments at end of report		57
Answered question		304
Skipped question		198

38. See below.

COMMENTS

9. Rate the level of training of the following individuals who work with your family member on the autism spectrum.

We have seen the gamut: Case managers from exceptionally wonderful to woefully inadequate/incompetent + some in-between. Para-educators: wonderful to so-so. Mental health workers: helpful to destructive. SLPs – generally good. Behavior specialists – the one we saw was counter-productive. Voc-Rehab Counselors – nice enough, but not of much help. School administrators – generally, not a clue, some hurtful decisions. General educators – mostly good. Developmental services – too early to tell.

What about us parents? We are the actual professional 24/7 unpaid supports

We (my husband, but mostly me, the mother) have provided training to his music and art therapists in terms of educating them about the disability. There simply are no music therapists or art therapists in our area who are specifically trained to handle ASD.

However, there are a great many educated and educatable people here. If special statewide workshops were held, there would be a plethora of creative and intelligent individuals who could be trained to work with the disabled.

I do not know but it does not seem that there is much, most services happen through school and since he can not have a IEP because he does not show adverse affect those services are not much.

I want to note, that we have advocated strongly for the people who are familiar with autism...not a lot out there~ Often paying for seminars and workshops that would help our child's one on one become more proficient in understanding his unique world. We pay a great deal of money to have as highly qualified a person we can...work with our child. As an educator myself, I see big gaps in what we provide for our children who happen to have autism.

Primary care physicians really need more training. Many times I am told, "This isn't my area of expertise", which is very frustrating.

My child is now in the local school system, who have known for 2 ½ yrs he would be there, he was there for Pre-K and is now there for K. They are not ready for him, nor do they show much interest in trainings. All is left up to his aide so it seems, with people at higher ranks basically stating whatever the aide needs just request it, but not much involvement with anyone besides the aide. Things have not yet been put into place for motor sensory issues, nor does it seem it will be.

Answers reflect the unevenness of teams. You need highly skilled program managers with planning time to coordinate activities recommended by highly skilled specialists, and time to train and supervise direct instruction staff to implement so that the program is not fragmented. The challenges mount when you add a layer of involving regular education staff.

I am my sibling's primary care giver. She is high functioning with Asperger's. Most difficulties come from lack of social cuing and training in social cuing and interactions. Due to the delay in diagnosis, she has developed other coping skills that have kept her in the community as a contributing member all these years. I have been trained as a respite worker, home care provider, and work closely with behavior specialists in my job, so I have a lot of experience with the autism/NOS/PDD end of the

spectrum. Living with an adult with Asperger's has been a challenge that I am meeting daily with the help of physicians and the network I establish while working in autism programs.

RDI Specialist: High Level of Training – Certified While we no longer work with an OT or SLP or developmental therapist, the people who we did work with through FITP were excellent and very highly trained and very knowledgeable! We no longer need the support of an OT or an SLP, although we do occasionally have re-evaluations that we pay for out of pocket for an SLP in our area with RDI training.

My child attended college in Vermont. Due to very inadequate support by disability services and the administration at the college, he was forced to drop out.

The people who work one on one with my little brother during school do not have any training on how to teach him and his special educator has not been providing any sort of programs for him. Thus his one on one aides have been trying to do their best (with no training with DTL) but he has regressed so much that he cannot even write his own name anymore (because they do not do the maintenance work). Overall I feel that the school systems along with the teaching professionals in Vermont do not know how to handle and teach children with a disability unless it is something such as ADHD. More complex disabilities such as Autism need to be handled more delicately.

DCF needs help with supports with dealing with children with autism and helping foster families plan accordingly.

Private OT's training – very knowledgeable; School's OT – inadequate training

We don't have a community or agency case manager in my county. All resourcing and networking and troubleshooting has to come from me, the parent. There is no guidance of any kind from the local mental health agency. There is no list of resources, no leads for funding, no support what so ever. It sucks.

This section filled out on how I perceived these individuals to be trained in AUTISM work, from their interactions with my child. I have no way of knowing what training these folks have had in working with Autism Spectrum disorders from some of these individuals. Under counselors I put "some" as one has a high level but another we had inadequate. We did work with an Autism consultant at public school. She has a high level of training.

I have organized some cross training of PCA's with the Summer School Training Opportunities to blend objectives and skills.

The Agency of Human Services and the DOE need to start talking to one another. Services for these kids are appalling.

10. What services are you currently accessing?

We're simply not receiving the amount of services we could be to help our child prepare for self support someday.

My son is Deaf and uses ASL only to communicate, his reading and writing skills are not adequate enough to use as a means of communicating. He works without an interpreter and is unable to communicate with his boss and co-workers. He had a job coach in school but after he graduated his has no one. His VR counselor is unable to be the job coach or provide an interpreter at work. My son is only marginally maintaining his job (he supervisor should have fired him for non compliance of the sick leave policy- he calls in sick all the time-but she feels sorry for him and keeps him working but only gives him six hours per week).

Barre Collaborative for Autism - 30 hrs/ week - they're AWESOME, but our schools and team providers (ex. speech, OT) need to develop much closer and respectful working relationship to develop consistent approach and consistent goals to achieve outcomes more effectively and more quickly. School is woefully unprepared to make accommodations to mainstream my son into school program.

St. Michael's provides all the accommodations needed and they are always available for the parent, even though he is in a College setting.

It was not possible to give accurate answers without being able to check 2 columns because a service may be frequent enough, but not address the need. Our example: SLP services: 4 times a week (2 hours), but delivered by an assistant who is not able to engage the student, so high frequency without meeting the need. Other: Music. Very successful with a past teacher 4 times a week; currently without success once a week.

Question number 11 (since there is no comment space): Unable to choose only 3 because there are some core services that help people and families to access specialized

services. Without case management and interagency collaboration (school and developmental services) it is virtually impossible to have programs across school and home settings that involve the same specialists such as behavior support, OT, etc. Without that it is hard to set up social skills groups, bring in sensory activities, etc. It is also impossible to have anything going outside of school without direct support workers, and ongoing recruitment is either the work of parents or a case manager . . . At other I would have added additional services: ** sex education ** direct support; ** music & ** sensory integration

RDI specialist intervention

None. My son is now in Virginia receiving services from disability services at Old Dominion University. He has a private dorm room and weekly visits with a disabilities counselor. If he had been able to receive those services here in Vermont, he might would most likely still be attending school here.

sorry this seems so negative...many circumstances and some services are just starting, but many things seem to be happening, but not appropriately. Social skills training for example, 30 minutes a week - no enough for this diagnosis and then when they work on the skill, it is with children with behavior needs so there aren't really peer models... Counseling for example, should be in a group where things could be pointed it...but nothing pays for group therapy with real outside of school counselors. No programs for groups of early teens who act like they are 8... it's tricky

My daughter is currently attending a special education school in MA.

There is no support here in our county for the family. My other 3 typical children have no support for their concerns, or how they can get training to help their brother. Too far away from the too infrequent Sib Shops. No know counseling to check in with for me, single parent, head of household, nothing. NOTHING.

Need more services outside of school, especially in the summer and school breaks. Need help with how to access respite care or train someone I know. Would like help with identifying appropriate extra-curricular activities--he wants to be in soccer or tee ball like other kids but lacks social skills for team sports.

1. There is a complete lack of summer services for kids on the spectrum. These kids desperately need continuity and a learning environment all year long to work on

their IEP goals. Yet services are patchy and thrown together and seldom help the child retain his/her skills. 2. Lack of training/pay for PCAs/respite workers/school one on one aides. 3. Difficulties finding and keeping respite workers/PCAs.

Parent training. More workshops need to be in the south. Most are in Burlington or Albany, NY.

Our developmental service is private. We do RDI, Relationship Development Intervention. We do not use any of the typical school related services as we have pulled our child from the public schools after two frustrating years of inadequate understanding of and attention to the our sons primary difficulties there.

All of the above services are done through the home. Public school staff, aides are insufficient, child is now home schooled and parents are responsible for all services or private hire of services to have the child's needs met.

The CDC only had one developmental pediatrician Dr. Ruffle who has since retired. My son hasn't seen a developmental pediatrician since the age of THREE. He is SEVEN. This 'system of care' is a joke and vastly underserving my child. He has services from 8-2 during the school day and that's it...no one cares if he sits in front of the TV all day like a lump. No one is teaching him to be a part of his quote "community" if there indeed is a community that gives a damn about these kids.

My child gets social skills in School (IEP) and Socials outside of School at the Stern Center. The skills outside of school have been more meaningful for my child than the ones in school and the outside ones are paid out of pocket.

Being able to access services is different from having someone available who knows what to do.

12. How has supporting an individual with an autism spectrum disorder impacted your family?

The EEE program not respecting the close family unit my son has. Not respecting our values in his educational plan.

calling in sick A LOT!

This is the hardest situation we have ever had to deal with, this disability is not easy. It gets harder each day. It is mentally, physically, and emotionally draining.

It's been difficult as a step-parent. I also parent much differently than my step-son's mother, even outside the special issues that come with his Asperger's. The step-parenting dynamic is tricky in and of itself, so it has been stressful and sometimes very emotionally challenging for me. It's been that much harder to create a bond with him and to have a relationship

It can be a lonely world when others can not see past the autism.

My son is profoundly deaf with PDD NOS. An autism diagnosis within the deaf population is almost unheard of (unless extremely low functioning) therefore wasn't even tested for when he was in school. After graduation I tried to get support for him and was turned down because he didn't qualify for Developmental Services. After constant advocacy, he finally was assessed and given the PDD diagnosis this August. We have struggled his whole life to find something that would help him but without success. We are totally on our own to try to keep him safe let alone support any kind of on-going training and support for his employment and independence. I am extremely disappointed in the mental health agency and feel that they have been lax in their attention to the seriousness of our situation.

There isn't enough financial support. I had to leave my job to care for my child, but supposedly my husband makes too much money for us to receive any sort of assistance, yet we can't make ends meet. Families should never have to choose between paying rent and taking care of their special needs child.

It is highly stressful to our family. We haven't any family around so when we do go visit it is hard for us to maintain without input. Many Dr's, School People, or other Professionals haven't got a clue unless they live this everyday. My husband works to take care of our family, I feel like a single parent running a lot for our child, our other children are impacted. My husband and myself just went out to lunch for the first time in 2 yrs, we never have family vacations for financial reasons, due to not being able to leave work it's our only income. Social isolation is a big YES, people don't understand, or they think your child is spoiled. Stress, everyone has stress but this is hard. It's worth it for our child, but hard on a family.

Has been very tough, but Mt. Abe and St. Michael's have been very helpful in all capacities.

This impacts on many levels. Despite funding our family has not had help to bring professionals and direct support workers with expertise into life outside of school. time . At this point as parents we are the only ones able to set boundaries and limits to be able to go out into the community since professional expertise is not available to train, supervise and plan activities by direct support workers. Within the home, life is built around the family member with autism; creating a controlled environment that reduces perseveration and behavior challenges through structure and limited access to video, audio, etc. When you can't do it there is guilt; when you can you live a restricted life that takes its toll.

No other family member wants to be responsible for the care of my sister. I take a lot of grief from my own children about how limiting dealing with her in social situations can be. My siblings are glad to send her to live with me (they live on the West Coast), let her pay me rent, and tell me they have families of their own. The last 3 family members who were responsible for her care died. These were our parents and an aunt. My brothers joke that they died to get away from her...like I would think that's funny, given the situation I am in. Requests for respite and help are met with silence....so I am adapting my life to fit hers and trying to teach her more social networking in the hope that she will be able to get out without me a bit more. I do get out on my own, go to visit family and friends for brief (2 day) breaks and then go back to deal with the sister whom I love. I'm no saint. I would love for her to feel freer and more in touch with my world. Short of that, I am trying to visualize her world and reach out to her.

I can not work due to the severity of his disability.

Aspergers syndrome is very misunderstood, even by professionals working in the field. A great deal of blame is routinely place on the child and the child's parents. Ignorance and blame on the part of education professionals have led to many incidences of extreme distress. My son has attempted suicide more than once in his life because of stress related to school. Many incidences of communication troubles in my son's workplace have been experienced, causing distress.

It impacts every aspect of our family. From where we go on vacation to how we function as a family. There is no free time or down time to meet our own needs which is why the items you listed above impacts the family.

Must be available to retrieve the child at school during normal school hours; typically get called to pick up child 3 times per week, making employment extremely difficult. Have been told I am disqualified from receiving assistance while the child remains in the home. As a single parent, I am barely making ends meet.

For 18 years I was held hostage by my daughters disabilities. Sibling issues are more related to jealousy due to the amount of time child with autism spectrum requires, although we make concerted efforts for one on one time with non-autistic child(ren). Overwhelmed at times with juggling all the balls, services and advocating for your child.

The insider/outsider games that the school plays with my son's IEP process, planning. Lots of polite talk but no meaningful actions. Half a dozen top notch expert recommendations with little or no follow through. Lack of integrity in their IEP response to his needs. Very distressing. I know the rules; they know the rules but still they philabuster or they double speak or they use semantics to avoid implementing the recommendations for him. Often they are not even costly, just differential in nature. They hire consultant after consultant, yet they will not invest in training for his para(s) so they can effectively implement these plans. There is no connection with home; no provision of services for parent training or for continuity to home. I feel like my son is doomed. I can't move, I can't afford to private hire. His future is being determined by a system that has no investment in his future.

My stress level has gone way down however after our departure from the public school system

The loss of income due to job losses creates a cycle of stress, social isolation and problems within a marriage.

Almost all of the above (he has no siblings, because of the above listed issues). There is no support, he needs 24/7 supervision. Therefore one parent must stay home with him/be there to go to the school at a moments notice when a crisis comes. We may lose our home as we have NO money (but we "make too much money" for government support -- of course). We love our child -- we just wish there were more support for him, and us!

Supports are lacking...

The only reason I have not lost my job is that I work for myself. My son's first year of school was out of school 24 days. And then sick on weekends and vacations. To say that a diagnosis of autism dramatically affects every aspect of your life - is still a colossal ***understatement***. Autism effects every aspect of our lives from the moment we awaken to the moment we go to sleep (if that is possible at all). Your entire world is forever changed, and there is never a 'break' . Parents are just asked to pull themselves up by their bootstraps and suck it up. A swift kick in the teeth from the diagnosis, to the delivery of services. The system of care is appalling, from the way the diagnosis is delivered to a family, to the materials they are given post diagnosis, to the transition from FIT to school system, to the day to day skills their children are NOT given and are federally entitled to through EPDST. The lack of services to help our kids communicate. All of it is just appalling.

13. Where is your child receiving his/her education?

child taught in hallway by IA

taking a couple of courses

Our son has his educational services delivered at his daycare. He has a one on one... due to extreme safety issues.

He attended Austine School for the Deaf and graduated in June of 05

My child hasn't started school yet. We are working with FITP. She starts EEE next year

He was home schooled and then went to the public schools

EEE preschool program 4 days per week, 2.5 hours per day

VT prides itself on being the "inclusion state' Yet it is failing to provide the school environment and the support needed for a number of older students with autism to remain at their local schools. It is also failing to create viable alternatives -- a continuum of placements. Parents cannot understand why it is not okay to have a residential school in Vermont that would offer many more options to spend time with family, while it is okay to send kids out of state, with all the hardships that imposes on families and kids. In our

case there was no autism expert part of the residential review team, or a state level interagency team convened to try to address.

Is out of school now and is employed with one on one support for 12 hours per week.

adult services

She left college after 4 unsuccessful starts over 20 years. She still dreams of being a teacher

We have opted out of our Pre-K at the local elementary school and are currently looking into private school for K-12.

Used to be a separate classroom inside the regular school environment but now he has just been sitting in a regular classroom doing nothing because he once again has no programs in place.

While at school, an individual room is where the majority of the day is spent as integration into the "normal" classroom has been unsuccessful. When aids are available or behavior escalates, he stays at home and the case manager comes to the home for "teaching".

School Services are a combination of pull out or in classroom

She is attending the only college that could support her needs - Landmark College in Putney VT that specializes in supporting students with Learning Disabilities/ADHD - ALL staff are highly trained in working with and supporting students who learn differently.

ACORNS program, Molly Stark Elem.

Family member is adult.

on the farm program 3 afternoons a week

Early Essential Education preschool in the school district

14. What are the interventions/treatment modalities that have been effective in working with your family member with ASD?

We have tried a number of different treatments. It is hard to say which have been most effective. He has always continued to make slow steady progress with whatever we have done.

strict daily plans, flexibility, braking things down with charts, talking calmly, giving his choices, the list goes on and on. One day at a time, one challenge at a time.

We have not had any type of help with our child on his autism disorder, other than @ school and they don't really know much about Autism

We haven't had the privilege of having been able to try any intervention or treatment.

The key component is a strong program manager who has enough planning time to develop and integrate activities across disciplines. That is the component most lacking.

Other: Music

social skills, peer modeling, and TEAACH would be great if we could get it.

Mom

Homeopathic Remedy: Bufo!!!

It would have been nice to try some of the things on this list. Unfortunately coordinated services were not available for my son when he was young and now it's too late.

although I am writing these have been effective... there are things that aren't available anymore. EX: Sensory integration is not available as there aren't any funds, counseling needs to be changed and there is no one to do this. social skills training done, but can't implement with current school situation.

Family Therapy

One-on-one direct teaching of social skills and life skills while living outside the home in a group home environment for 18 months just after her diagnosis.

my daughter was never diagnosed with an ASD but I believe she is on the scale somewhere based on my own research, albeit high functioning. Mental health, school, and pediatrician were not able to help her. She limped through high school for three years and graduated from an alternative program. As soon as she completed the required elements for graduation we were told that she had to leave the school, despite her being only 16 and having been at the school for only 3 years. She is working now and living on her own.

I would like to see a "Friends" program started in school or circle of friend etc. To build social support and acceptance in elementary school through high school

We use social stories but not in the Carol Gray model.

A few things have been "tried", but to no avail. Our son got tired of doing things a certain way, OR the adult (school personnel) hit a road block and stopped. He MUST learn Social Skills. He does NOT have the opportunity being an only child that has shown himself to everyone in our town that he has issues therefore has NO friends, nor anyone that would be willing to watch him for any respite time for us. The school acts like they cannot possibly provide him with any Social Skills training. That has ALWAYS been a huge issue -- them not doing what he needs most.

Many of these have been touched on and need more intensity. Funding is not in place for wrap around programs.

There are lots of interventions..and we have tried many. I would share that the ONE and ONLY PROVEN scientific methodology is ABA. ALL of these kids should be given access to this treatment as a matter of course. It should be standard protocol. The research is there to back it up. Until all these other methodologies come up with 20 years of proven replicable research, we should stop spinning our wheels on what to use and PICK SOMETHING THAT IS SCIENTIFICALLY PROVEN TO WORK. ABA ABA

17. Do you have suggestions for the preparation of individuals with ASD for living independently?

Intensive program taught by qualified, experienced professionals who are specifically trained to serve individuals with ASD

Are independent living skills something that could be worked on by a group of individuals as well as one-on-one with a coach? (Similar to the Montpelier High School's "Apartment Program" -- I've heard of it, and was intrigued, but don't know how it's going.) That way you would get more of a social piece, too. Perhaps facilitators would need additional education/training. Something to think about....

Social and functional life skills need to be made available as early as possible in the individual's educational setting/plan.

More apartment programs expansion of existing apartment program in Montpelier to include overnights with training on how to actually get independent.

There needs to be more trainings for things of a real life nature to help us learn how to teach our child things like cooking, cleaning, bathing, etc..... These are things that can't be taught at school.

I am from Maine and I know that they have a good system with group housing for adults.

Beginning in sixth grade, these individuals could use a life skills coach.

My son is only 16 but this issue is approaching and I am very concerned. He is so easily influenced by others. I really can't answer this question. my suggestions are one on one eye contact communications with child. that when having a conversation show child you are interested and are listening to what is being said by them, it is important to the child they are being heard. When correcting a child try not to let others interfere with this because it can set off loud behavior problems always do this separately.

Many meetings to make sure the student is learning across all settings. Find out what the individual and family wants. Make sure the staff is trained in the life skill area. TEACCH has a lot to offer. We need more training in that area. We need funding to get started and to keep going. Some will not live independently and will need a higher level of supervision but that does not mean that they should not have their own house or apartment with staff supervision.

I do... and have written to Gov. Douglas ~ received a form letter thanking me for my input.. We need people to be willing to do the right thing... to be bold, take the steps needed to make group homes work... The bottom line always comes back to money~!

Diagnosis within the deaf population so we can treat the autism rather than assume they are cognitively impaired!

Develop self help skills and self confidence

Existing school system is totally unprepared to help my son develop skills for independent living. They are struggling to try to see how they can mainstream him into academics to reach his educational goals. We are struggling to ensure that the school will work with his communication tools (ex. PECS) in order to reduce frustration that could lead to behavioral issues which will inevitably remove him from the classroom setting and reduce his time on academic efforts.

Sure- Like mentioned above, apartments for rent in Burlington, with an "active manager" for "consulting" and safety.

Transition plans must be strong and include opportunities to practice a range of skills including social, employment and daily living. There need to be people planning and implementing those activities who are knowledgeable about learning styles, accommodations and supports that can work for individuals with autism. They also need to be knowledgeable about sensory issues and match people with setting they can be successful in. For this to happen there really needs to be collaboration between school and home based programming. That cannot happen if the primary after school component is funded through family-managed personal care, which puts the burden on families to create activities and programming, and to recruit, train and supervise direct support staff.

Better funding to schools

-more community support post high school *** -more social opportunities with other disabled adults (currently Howard Family Services provide one dance at Valentine's Day -a house available for day programs instead of a day care providers who doesn't have places to go except what parents already provide or come up with suggestions (i.e. picnics, hikes, sailing) -more summer camps for young adults to attend like the Partners in Adventure Day Program -field trips -more inexpensive programs for clients and their families such as adaptive horseback riding lessons (\$180. for 6 sessions) when you are lucky enough to find openings -some quality of life opportunities -more available transportation for adults living in the surrounding communities such as Jericho

Begin in middle school developing independent skills. Allow students to make choices & mistakes to learn. Opportunities to do shopping, food prep, laundry, etc in home/ or apartment situations.

In our case, it's been tried several times and has always failed due to lack of social awareness and skills to live alone. She can be alone for a day or two, but living alone inspires fear. Preparing adults to live independently would demand an intense program of supported living and aid in bill paying, jobs' demands, social skill training, and supports for both the individual with ASD and family members for an extended period of time.

having programs that focus on INDEPENDENT LIVING appropriate for the individual.

Early intervention and modeling. Starting early with 4year olds and teaching them how to do laundry and fold clothes, basic cooking and cleaning... Montessori model appropriate to age.

More supported housing options.

This cannot wait until they are adults or entering adulthood. The skills needed to function independently need to be addressed and fostered early on and built upon as they grow. Then the transition is less traumatic and more successful once they are older.

intense life skills program

As my brother is only 13 I do not know what is in store for him as he gets older.

As of right now I feel that he is no where near being independent enough to live on his own.

finding funding to train and work with people. Individual skills are so needed for social situations and role playing and I don't think this happens enough in school as there are academics needs as well. I think having people work in groups outside of the home, doing more PCA kinds of things - but as groups like 3 together, so they can function not only on how to do personal care sorts of things, but the socialization and working together as a team to problem solve.

For my family, my daughter will never be able to live alone. My biggest concern is finding a place for her to live after school. Right now there is nothing in the state of VT that will meet her needs.

If services were provided by competent professionals and schools allowed parents to be a valuable member of the educational team, there would be many more individuals with ASD who would be able to live independently.

help develop skills in making life decisions (budgeting, use of leisure time, personal relationships) root the learning in as many different venues as possible to encourage generalization of the skill.

Need to be taught daily living skill, i.e., cooking, cleaning, laundry

Supported living consistent with level of functionality. Transportation needs.

Opportunities for social interactions.

A practice apartment model in the last 2 years of high school or vo-tech would be ideal.

High schools need to have start transition plans at age 16, using a MAPS or similar program. Living arrangements and places to live independently need to be

arranged. (UCS)? A list or sources of employment, should be made available, for folks with various talents. i.e., clerical, computer/data entry, vocational etc. (coordinated by high school and local employment agency. Colleges make accommodations and courses for kids, dorms, mentors, jobs on campus.

More life skills training within the public school. In skill areas like cooking, housekeeping, service calls, emergency response and the like.

A typical peer helper that would get a stipend or payment. That way my child who is high functioning WOULDNT feel like he is getting "extra help"- he would feel like he has a good friend(which he does)- who is the same age and helping him. I hope that came out right.

Proper supports for the person to be able to work in their skilled area.

Hold schools accountable for transition services, start at 14. My son's school's not making connections to the community and "real" world - his 17 years old.

SOCIAL SKILLS!!!!!!!!!! Life skills. Job training. Mental health support. Financial support. Good & continuing access to health care. Housing. Livable wage. Transportation.

Strong mentor relationships.

Parents need to have more flexibility to choose appropriate program for their children on ASD. Inclusion is not good for every child.

More options for alternative schooling.

More intermediate homes with assisted living. More programs to start teaching them life skills in manors that work for their brains.

We need centers to address the specific needs of the autism community, with expertise available to families, individuals with ASD, employers and staff who work with individuals with ASD.

Life Skills should start younger. When you have a 10 year old who is high functioning but cannot use a toaster on his own out of safety concerns, that is a real issue. Things such as crossing a street and life skills should also be taught in school. More therapist with training in Autism should be available. Every professional worker should have a requirement for their license be that they need to have training with individuals with Autism or other special needs.

We have to stop thinking K-12 grade and be teaching them for 0-90 years of age. There needs to be access to assistance passed the age of 18 or 21.

well-trained special educators who use community supports well-trained

18. What supports have been most effective for you and your family?

ABA

We were blessed with a great para-educator for most of high school. Also, a year at the local vocational center, with an outstanding instructor. The vocational center model -- a small group of students working together to learn a particular set of skills -- seems to me to have potential.

The behavioral specialist that does DTL with my son is a god send!

Speech & Language, social development, accessibility to augmentative communication devices, OT & PT services.

support group i belong to

slp and ncss case manger and also preschool teacher

school special educator.

early intervention medicaid waiver funding since age of 5 ssi funding PCA strong slp /augmentative communication supports

The supports that have been the best for our family are the Augmentative Learning and Movement Center (old school had them as consultants), VPIC, PTP, as well as the great online support groups for parents. So not really anything the government has offered, lol.

I have been very lucky to have people in my sons life who truly care for him. We have an great elementary school, and the special educators and teaching staff all go out of their way to do what is best for him. In addition, I have had the same personal care staff for a number of years. One has been with us since the beginning,...8years. The other was his school para and has been with him for 4 years. Knowing that he is surrounded by really good people is the most comforting feeling and I believe it helps him to form those special relationships.

Time away from our child w/ special needs. This rarely happens. We get burned out and cannot effectively be "on" all the time to model, teach by example, or even be patient enough to go over again and again the behavior modification protocols.

A great therapist, medication, some of the best case managers in the whole world.

UCS counseling, family therapy at UCS with a family counselor as well as an individual counselor. make sure each family member has there own individual counselor even parents it help relieve stress and keeps it away from other family members .

Having consultants come into the school to give recommendations. The school staff has not had much training in autism and very little opportunity to apply it to develop experience.

Our FITP team... out of Colchester. It was a strong team. We had an amazing developmental educator, SLP (that we found through my district) and an autism specialist who works wonders with children on the spectrum. Our OT and PT were very involved, however neither had any real understanding of children his age and what was appropriate for his age and ability.. Our son spilt his nose wide open in the care of the PT, sooo accidents happen. The more people we have trained in understanding the autism the better~ We also have a post adoption worker who is our life line at times. Our sons IA is an integral part of our sons life and ability to function in this world.

a unified team effort to deal with some issues - we don't have enough team meetings to make this happen.

There needs to be more supports, family support groups or meetings, at a local facility or the hospital. There is NOTHING in the Northeast Upper Kingdom of VT, many things are in Essex and in Burlington, but it's 2-2 1/2 hrs away. We need to up the supports to Families in the Orleans County. Autism numbers are climbing and many families are suffering, you can't drive 2 hrs or more for a support meeting or training when you need to pay for gas as an extra expense. I have to drive our child to and from school daily and it is literally killing us in gas money.

Barre Collaborative staff, leadership, and education programs for families of children with ASD.

any financial supports available, including the "flexible family funding" grants.

Caring person/family centered public school who worked with my son and myself as intelligent formed people. And my own expertise, training and home life planning and application of supports.

* Special educators skilled in direct instruction, visual supports and how to engage students through their special interests. * Direct support workers who happened to be college students who were conscientious about preparing for work; using accommodations such as visual supports; carrying through activities; and flexible enough to engage our kid and avoid power struggles. * Home-based case manager who was a special educator and had experience with adult services, able to plan activities and accommodations and supervise direct support staff. * OT knowledgeable about autism and sensory integration who planned and helped us implement a successful oral motor home program to decrease saliva. -- Also helped to develop adaptation of ALERT program adapted to identify arousal level * Regular education music teacher who recognized talents and built on them to include our kid without support in music class at elementary school. * Kindergarten teacher who viewed our kid as her responsibility like any child, and an integral part of the classroom * Independent Evaluator at late elementary school who demonstrated that our kid could be tested and gave hope to do academics. * Other parents, who helped us learn about developmental services and other resources, and supported through the years. * Attending conferences, being on list-servs etc. that have led to learning key techniques that work our kid, including TEACCH

schedule and visual supports, Carol Gray's social stories; etc. * Psychologist who specializes in autism who provided home based social-emotional activities for direct support and parents to use with ongoing feedback and follow-up

Personal Care has been amazing. However, I am concerned once my daughter turns 21 this will be lost and then I will have no services to provide supervision when my daughter is home and I am working. This is very stressful. Also, the Career Choices program through the Community Access Program has helped my daughter to maintain employment with one on one support. This makes her feel valuable and productive. I constantly worry that if any of these services lapse what will happen to her.
counseling and help within the school
PCA and IA

-school programs available when he was in school such as life skills, attempts at job training, social skills, swimming, etc. -a very caring para educator who went well beyond what was expected of her.

Respite care. Behavioral supports. Need wrap around services that also include behavioral issues at home (not just in school or in the adult program).

My education in special education needs and ASD, lots of reading materials adapted to the level of comprehension of the individual, mental health workers/counselors for the caregiver, an understanding work environment for both parties, and willingness on the parts of all folks involved to try to see the other side of the picture.

The school experiences have been absolutely GREAT so far - can't say enough about the professionalism and empathy of teaching staff over the years, both in our own small town, and when that wasn't sufficient for our son's needs, in the small school for autism outside our school district. We have also been blessed by knowing a teenage & now adult boy from our church that has been willing and able to provide respite for us occasionally. It is a good fit between caregiver and child.

Short term behavior intervention through CUPS. OT and PT Speech and Language spec.
access to educational trainings, choosing what is appropriate for my sons needs not what is appropriate for one.

FITP ! - and they actually funded our RDI specialist for a year before our son turned three.

My son recently received a home and community based waiver-- I'm hoping it will make a difference.

Funding, shared living providers, behavioral specialist, respite
Personal Care assistance - however, it is hard to find and keep capable providers. When we do and skills are improving, hours are cut. Our son needs to then regress, to regain the hours he needs/needed to make the progress again.

PCA and flexible family funding. But it is very hard to find a good PCA to work the hours needed

PCA, therapy, sensory integration, music at school helps communication tremendously.
Peer navigator support has helped.

Respite care was huge, it was the only time I was able to things with the rest of the family. The biggest hurdle was we had to find someone ourselves. This was very

difficult when we had just moved to the state and didn't know anyone. I have never seen a state put so much on the families, major stressor.

Money

The support of the BCBA.

Respite and pc hours have help me get threw the tough times. I have a really good Respite and PC workers.

1) Private OT at Philo addressing multiple challenges including sensory defensiveness and integration/processing difficulties. 2) Family Therapy 3) Attending various conferences in/out of state and reading current literature

SSI and children with special health needs.

visual supports and a good sensory diet

Most of my daughter's case managers have been very supportive and helpful. The fact that I have been in the education field for 25+ years and done graduate work in special education certainly increased the sense of self support... I had a sense of what I was seeing and what to ask for/advocate for. The Parent to Parent network has also always been a great source of information and support.

The Family Infant and Toddler Program was incredibly supportive, informative and caring.

Had little or no support. Throughout her school years, I was treated like I was her disability. Because she didn't have 'disability' on her forehead, her needs at school tended to be ignored and still are at the college level.

Respite and PCA services. Other families - support groups and online support groups.

Internet resources with information about the condition. Information from family member in New Jersey who is a mental health care provider. NAMI Never diagnosed by pediatrician, mental health care provider, or school. None of these resources considered this diagnosis as a possibility. Her symptoms were not recognized. The only thing she was ever diagnosed with was depression.

Therapeutic horse-back riding, BART program skiing program at Bromley, skating with dad. His ot, getting him to try new foods. Flexible family funding.

RDI!!! Look carefully at my son specifically and support where needed most.

Willing to come to home to work with him. Willing to come to school to extend appropriate services into the school environment. Public school however will not welcome this critical member of our team. Another reason why we have gone. Since RDI folks must be child psychology licensed the approach very holistic. Flex family funding.....not a lot but enough to take the edge off a few small ticket items. Case manager spectacular. Child Development Center /Burlington and CSHN - busy, but focused on our needs when we need them. Web information and chat sites like Autism Support Daily and the Asperger's Assn of New England.

Having a multidisciplinary IEP team with Autism Specific Training in all areas of disciplines. Our team has skills with collaborative teaming and a family centered, strengths based approach to education. Family follows the behavior plan, and is educated in the child's disability and is a valued partner on the team. Having a HCBW, although very small, is a comfort to have. Having a DS case manager, even though I don't really need her all that much now, I will in the future as he attends middle school and transitions to adult life.

The PCA, The IEP, obviously.

The designated Agency has been most helpful in creating independence for the family member. WCMHS.

Having the Washington County mental health agency to serve my oldest child. Personal care services is helpful but finding people has been hard lately.

When the school - CVU high school - finally got someone from the "outside" to consult. We are working with the Howard Center (at school only). Their staff are knowledgeable and know what they are doing. Also the introduction of a psychiatrist in my son's life has been a lifesaver for him and our family. We access her thru CSHN.

Flexible Family Funding. This one comes to mind as it is a little bit of money as we are a one income family and STRUGGLING.

Other autism families.

Having my child w/Baird Autism Program

A well-trained EEE staff. Our EEE staff has been trained in RDI, TEACCH, ABA and Floortime and used all to tailor a program for our son. Medical treatments that our son become healthier.

FIT was the most supportive group to date - all services were coordinated and delivered by ASD trained professionals within their area of specialty - ie: speech, OT, PT, behavior, etc. The draw back was that they were just getting to know the needs of my child and our family before the 3rd birthday and then we were poorly received during transition by the next group - EEE.

support groups & respite

FITP got us started. And now we just bumble through with out much support or knowing what really we can get from our school district.

Researching outside information and educating Vermont staff about best practices for individuals on the autism spectrum, such as TEACCH.

Social Skills and Occupational Therapy. They are expensive to the family and not readily available.

family, friends, school

special education

19. What supports have been least effective for you and your family member?

The lack of an appropriate school program/learning environment, and the absence of other available options other than public school setting to receive therapy services i.e.- speech-language, ABA

Speech services have been useless!

Respite, after school care, recreational programs within the community, adaptive sport programs available within the school setting, lack of training /information shared with the regular ed. faculty, sensitivity training for peers, school faculty, frequency of OT & PT services, community based social programs

useless behavioral interventionists that cost 90 bucks an hour and do nothing
Having to BEG for personal care hours, and never being
approved for enough.

I think when books or reports come out saying their methods cured the autism it is difficult. We spent \$30,000 over a year and a half on Son-Rise. I personally home schooled him for 40 hours weekly during that time. It was heart wrenching to not see more dramatic results. We've tried diets, mega-vitamins, anti-fungal, etc. It is hard not to feel hopeful by some of the "stories", but then it is disappointing.

Linda Mood Bell was a total rip off. We spent almost \$12,000 for nothing and were not reimbursed by school district, insurance or any entity.

Schools and people that just don't understand this disability and people who are inflexible.

outside members have been least affective . I feel others should leave this to professionals

When a special educator that is trained in reading issues is our case manager.

The state push back, the endless paperwork and lack of understanding in some of the agencies when we tried to find help... The lack of funding. Especially around PCA hours and the small amount we pay them from ARIS... they are usually doing a job that requires more than ten dollars.

Nothing can be worse than nothing.
strict behavior modification

School special ed director, school special ed/case manager
future adult training is not helpful to us at this point. We are trying to concentrate on the day to day trials and get through them.

Grouping all "special ed kids" together. The range is from A-Z. Not Good!

* Professionals who claim to have autism expertise and do not. * Professionals who are not perceptive or patient and instead precipitate power struggles * Professionals who present as knowing all the answers and do not want to hear what we know already, and what has worked and hasn't * Lack of continuity in special education: Starting all over with a new school team every year. Writing a new IEP from scratch each year. Etc. * Special education services that have been fragmented. Examples are lack of coordination between purchased autism services and school services. OT, PT and other specialists delivering services that are not integrated into the rest of the day. * Goals and services in an IEP for years that don't happen. Example: sex education for a youth. * Behavior support that was not based on in depth functional behavioral analysis. Example

-- sensory reactivity not included. * Consultants who make recommendations about what others should do who are not there to roll up sleeves and do with staff that needs to carry out. * Consultants who do not take responsibility and hold people accountable for following through. * Schools hiring paraprofessionals who do not have training, experience or ongoing supervision and support to be able to do the work. * Schools that pay lip service to inclusion but actually keep the special and regular education departments apart. * Benign, unnoticed discrimination by schools. Our experiences: exclusion from field and graduation class trips without team discussion; sitting with aides across grades in the cafeteria instead of classmates, etc. * Funding that we are unable to use because there is no one to hire to run a social skills group; do one-to-one counseling; plan and oversee activities by direct support workers, etc. * Unsuccessful attempt to use the Act 264 process -- no help, no state level team or collaboration.

public school district

community support - we have support in the community for 20 hours a day, divided up between 2 providers. One started at 8:00am when there were no community activities. The workers all want to have two clients with 20 hours each (so they can be full time); so, you have to choose either morning or afternoon and then the few programs available that are linked to Howard are usually around 11-1:00 so you can't have them participate unless you, as the parent, are able to provide it yourself. no housing for a day program where staff could work together to provide the above mentioned opportunities. If they had something such as mental health has (Weststaff I think)it seems to me it would be less expensive.

"Let her fail. Then she'll learn how to do it right." "Put her in a home...." Denial that the problems of ASD don't go away and must be dealt with for life by everyone in the family

Without the above-mentioned caregiver, we are stuck with PCA currently working with our child...small town & not much labor base around to look for another helper. Also, there is a lack of places to go with our child that can be functional & enjoyable - currently the best place is indoor pool/workout facility & pizza, but it's 45 minutes away and over a mountain (!) which makes it a bit hazardous in inclement weather!!!!

The short term intervention through CUPS. No support when in grade school. IEP ineligible because of grade level performance. Social and Comm skills not grade level.

Community Associates, while the FFF monies are somewhat helpful, I am not sure how an organization that supports something like 140 individuals needs to have 70 full time staff with a budget of 5 or 6 million dollars. When I worked out the numbers it came to something like 300,000 per family. As we only receive app. 1K per year, I just think that there may be better ways to do things so that families could have the supports that they really do need or other options available to them.

Blaming parents and kids is not helpful. Ignoring requests from parents and kids is not helpful.

lack of funding for extra support, having to pay \$600 for shared living provider on my own

Personal Care assistance/respite is the only service/support we have received that was not covered by Katie Beckett or out of pocket. The entire dysfunctional system of what is accessible and available has been ineffective for my family.

The School system!!!!

Well - things start to happen and seem great, but then they backfire or people quit their job and someone new needs to be found. There must need to be more quality of payment for people trying to work with families.

behaviorist and people who come and go

Other than the BCBA, the school program is very inadequate to meet the needs of this child. What may be considered by some to be the least restrictive environment, is the most restrictive environment. If the home school route is chosen, no therapy services will be provided. Special Education should not mean that you are placed in a hallway with someone who has no training or experience on Autism.

Case management

School services are not comprehensive enough and at times have been counter to what's recommended for children on the autism spectrum. Requests for services are often met with an adversarial response when advocating for my child's needs. With all that accompanies raising a child with special needs, having to "battle" for school services is not only time consuming and physically/emotionally draining, but it feels like a full time job, which distracts me from giving my child all that he needs.

Finding any supports for home after my son began Kindergarten. Services were wonderful before public school began and not all services are confined to school.

School system, especially management. The process for "getting into" the mental health system in VT... having to be IN CRISIS to access appropriate services certainly was not effective and quite possibly interfered with progress that might have been made if we could have accessed services earlier in her life when we first started asking for help - but her behavior wasn't severe enough.

The public school system has been a challenge for us in dealing with our child with PDD. It has been very different from the experience with FITP. The Public school system has been unorganized, inefficient, lack of leadership and pro-activity, lack of vested interest in child.

Howard Center case management.

Public school system guidance counselor (CVU) made situation much worse. Informed us that at the age of 16, after less than 3 years at the high school, she would have to graduate and leave the school because she had completed the mandated requirements for graduation.

Summer school service too short of a day. More time with speech teacher more time with any special education class. Someone with music therapy qualifications. IEP meeting too short to few folks invited.

The entire public school experience!! Including non-adherence to FAPE but the fight to provide for my son would mean leaving him in the system that failed him in the first place for some undetermined amount of additional time: with the exception of one

marginalized Autism consultant who tried her hardest and a WONDERFUL OT. The waiver option to help with the above.

Unskilled or untrained supportive staff. Good intended, but untrained staff: Para's in school environment, Having to train PCA's is a bit of a struggle fitting in my life, but is a necessary evil.

State of Vermont has been pretty good. I am dissatisfied with some of the paras within a school. Some just don't care- and that is the reality. I am NOT referring to anyone in particular- but that is the truth.

The problem with our son's services is that they are all mostly school based. They are not making connections to home or community. I also am trying to get more than consultation time because "as needed" on his IEP is not working, will be trying to get weekly consults. Not enough mental health providers with expertise in children with ASD. It also was an area nobody was looking at until I started seeking help in this area. School never wants to get involved with the mental health piece. Lack of access for support in home and community - trained expertise. We have PCA's but that's not the same as having access to someone to do ABA etc in your home.

Untrained people working with our child (most all professions). Lack of/limit of ALL supports.

The lack of the adequate programs in school system. The school staff not being trained to work w/kids w/ASD. One program can not fit all.

We need better access to doctors here in Vermont and outside VT. We have traveled to MA General for treatment. Training for doctors and nurses here in VT.

pediatrician & getting providers to commit to the time we need. 1 hour each week is not enough!

E.E.E. as delivered by the school district. Case manager is weak and also functions as DE and SLP. No current training in ASD nor does she possess relationship training in how to work with parents. Because she is weak, there is poor team communication, and inconsistent service delivery of services my child is entitled to. This is a difficult struggle and made worse by the district that is unfairly compromising necessary services in lieu of the "funding" excuse - even after they asked for, and we granted them, the ability to bill Katie Beckett/Medicare for services provided on my child's behalf. There is no coordinated ASD program that follows State White paper guidelines or contracted ASD Behavior Consultant's recommendations, or recommendations made by the Child Dev Center.

The school district. I should not have to fight for his services. There should be a list of this is what you can get. And nothing is offered. I have to ask for everything. And there are services that would benefit my family and children but no one is willing to offer them up. It would be great if there was a handbook of this is what there is, this is what you can do with it, and this is what you need to do for it. It would be even better if you could just get all services your child needs with one form. I have found that the community around autism is at odds with each other and not working together. There is no grey. It's black and white and if you don't agree with me then your opinion doesn't count and you are just wrong. So I have retreated. I have done my best on my own.

Case managers who don't believe the diagnosis because child present as "better" Inclusion in the public school setting was ineffective and detrimental to her development.

The "supports" that the school has offered my Child. They tend to not have the appropriate training or understanding of the disability and they use the time away room excessively.

This is a circular question, implying there have been supports to comment on. There have been virtually none. Difficult to critique what you do not have.

Voc Rehab and other Adult services have been totally ineffective

33. What are the interventions/treatments modalities that have been effective in your work with individuals with ASD? Comments:

Being in the pool or lake with the youngster. Teaching water safety skills as well as swimming. Lots of water play leading to independence in water over the head. Changing room routine: personal hygiene, social interaction, undressing and dressing.

Getting as much training in all approaches to kids with ASD and then choosing what kinds of approaches work--show results and progress for the individual needs of the child. Just because something is not empirically researched does not mean it is not effective. Some of the approaches that garner the best results do not lend themselves well to empirical research.

I have had to adapt social stories to use stuffed animals and puppets as I found that none of the Asperger's kids I work with could understand the two dimensional figures. The three dimensional works great.

Consistent routine Clear rules, limits, and expectations

Dance/Movement therapists offer a movement approach, following the child's lead to build a relationship, increase of circles of communication, work on sensory issues and address other relevant issues through movement, play and words. We find that this is a very good medium to engage children on the spectrum and that it helps integrate the whole person and helps children develop a sense of self.

Integrated into a fun filled summer camp.

We run afterschool programs and full day programs during school breaks, including summer and school vacations. Our focus is educational support, enrichment, recreation, physical activity, and positive youth development. We have had participation by individuals with ASD in both types of offerings, afterschool and full-day. When ASD students participate, the school may provide supports at similar levels to those provided during the children's school experience. We have also had students who receive partial support through the school and partial support through other resources. Some ASD students have

come with no external supports, and we work with them. Primarily, our programs provide an inclusive environment where students can interact with their peers in a different environment with different expectations from those of the school day.

Intervention depends on the individual needs of the child/young adult not on a specific program. Many of the "programs" have similar components combined or labeled differently. Interventions appropriate to other children/young adults with significant learning challenges also may apply.

pharmacotherapy

The Fokes Sentence Builder and Ed Mark programs have been successful curriculum instruments. The use of these supports is focused on generalizing this information to the community.

Youth and adolescents with ASD have access to community partners who provide special services. Very few staff in this agency have training in this specific area. Services are usually provided through the public school system or through separate local community DD providers.

The only programs that seem to be working on a consistent basis are modeling, separation of senses (ie: separating the senses (sound, touch, smell,, etc.) in order to focus on one at a time, and long term assistance/family members/home placement. Our placement requires familiarity over years to gain trust in order to overcome obstacles. Constant changing of approaches/staff/programs is where you are defeating yourselves... Focus on people and individuals and throw the rest of your experimentation out the window....

Student is in a classroom utilizing Responsive Classroom strategies.

The list above indicates the complexity of approaches for children/adults with autism. Because each person on the autism spectrum is unique, an individualized program must be developed, assessed and updated continually. While FC may work for one student, PECs is the more appropriate for another. Many individuals have challenges dealing with sensory processing and benefit from approaches to support needs, de-sensitize areas and promote exploration are needed, but this is not Sensory Integration therapy per se. We as a community (regional areas in VT) need educators and providers with expertise in specific areas and a basic grasp of all approaches. We need to share our expertise and collaborate with others in the area. We need to avoid a single-minded approach which looks at everyone through the same lens.

Lunch bunch in smaller area with 6-7 children and 3-4 adults (paraprofessionals, teacher and principal). We work on communication, social skills and enjoying each other's company.

psychiatric services

My staff provides support services to children and students who are deaf and hard of hearing and their family and school teams. Their area of expertise is deaf

education. They work in collaboration with teams to provide for the whole child/student but knowledge and experience with children on the spectrum is limited

I am now teaching in another school. In my old school district the school contracted the Autism collaborative and I saw the most progress in a student from their work.

Efficacy and availability of services really depends on the individual's needs. Some students with Aspergers, for example, benefit from inclusion in the regular school program, with supports such as case management, counseling, behavioral intervention, special education services and social skills training. Others may have more extensive needs.

I am a classroom teacher and am not familiar with what many of the above terms mean. Usually when I have a student with ASD the interventions for my classroom are determined by need and effectiveness. These are often determined by special educators who support me in the classroom.

TEACCH Structured teaching for schedules, visual supports, structured tasks and independence training

informal picture exchange

we use hippotherapy for gross motor, fine motor and spatial awareness development as well as in supporting behavioral and communication development

HowardCenter CRT program has inadequate services for the ASD adult population. There are several clients who don't have proof of a ASD diagnosis before age 18 and are denied developmental services. The services here are null. There is a huge gap in providing effective treatment and services, i.e., community mentor support, respite, behavioral and adult daily living plans. They cannot do it on their own and case managers are not equipped to be intensive enough to provide daily 1:1 support. This is exactly what is needed for this population.

Wrap around services of the Addison Northwest Supervisory Union/ Counseling Service of Addison County Autism Project.

Paraeducators in my school receive some training, during times that are carved out of the schedule. There is a limited budget for it, and people are sometimes volunteering their time to organize and provide training (as well as to receive it).

psychological services

Not and over reliance on DTL. Good SLP can do wonders

Not all of the above approaches are currently used in my setting, however, I have clinically seen their impact in other settings/experiences.

use of routines

I have not worked directly with an individual with ASD nor a family member, but I am on a list serve and the family members use that a lot. They share info. about conferences, surveys, media articles on ASD, support each other, and give ideas of where to look for help they need.

PT/OT Swim program

Job coach, on the job training

When home and school are aligned in their approach.

A combination of methods designed based on family preferences and student strengths and interests has always worked best. None of the above interventions alone has been successful.

Firm, fair and consistent teaching and behavioral strategies based on years of experience with students with intensive needs. Having high yet reasonable expectations of all students, expecting them to do well while providing them with the supports (sensory, communication) that they need. Not using their impairment as an “excuse” for misbehavior or lack of social skills but provide them with the skills they need to be successful. Social skills development is THE foundation upon which all other skills will be based. Emphasis on academics without working the necessary social skills is a huge disservice to students with ASD. Efforts to disregard the importance of social skills in order to concentrate on academics is a misguided approach that needs to be addressed. How can we as professionals make the determination, by concentrating more on academics and less on social skills, that interacting with peers, participating in community activities and maintaining employment is less important than reading and writing?

Intensive speech-language intervention

We are beginning to implement Michelle Winner's curriculum on social thinking and perspective taking which we hear has been very effective. Just as a comment on the above question, there are items in the menu that could be effective. It's just that we have not used them here to date.

One on one play dates with a normally developing peer.

Cranial-Sacral Therapy

These services are available to some people in some areas of the state, not all. Some of these types of services are not available in most places due to a lack of trained professionals.

34. Please rate your level of qualification/extent of familiarity with each of the following: Comments

Autism Specialist in our district has been the most invaluable source of support this year. Taking Patty Prelock's class twice for credit, and the actual children are huge! Frustration is that training may not coincide with having a child on the spectrum in the past. Support staff absenteeism without adequately trained people that can or are willing (they are often afraid) to step into the situations when suddenly needed. Insufficient spaces to work with children individually when they are upset, and needing to maintain their dignity. Time for the team to meet together as support staff are not always available before or after school, and they are tightly scheduled throughout the day, as am I as the Special Educator. Basically everyone being stressed maximally, yet having to take into consideration the needs of the child first with grace and serenity.

Extra time to communicate with the parents of the children I work with is most essential for the team to work effectively and to put aside any distrust that can arise.

Lots of happy, physical playing out of doors. A lot of speaking directly to the child. Singing real songs and made up songs. Encouraging energetic movement away from repetitive, obsessive behaviors. Hugging.

STARRS Bay Area CA LoVas, how is that spelled? North Carolina State Autism Programming Wisconsin style intensive behavior, discrete trial models Lincoln School Model, Sacramento CA

Movement therapy - Master's level training with 20 years experience

high level of training in family therapy and home based support services

Combination depending on individualized educational program, needs of child/young adult, family, dreams, etc.

Need to educate physicians as to the potential medical and nutritional issues.

Approx 10-15 years ago, I was trained in facilitated communication (to be a facilitator). Our agency (in NYS) used FC in its day treatment program for adults with significant developmental disabilities, including ASD. Our agency then quickly abandoned this approach when research demonstrated the inaccuracy & ineffectiveness of FC. So although trained, I do not use FC and believe it would be unethical of me to recommend its use.

I am currently teaching Human Services at the HACTC. I have a background in

special education and for 18 years was a school principal in a building that housed 2 district programs for significantly disabled students in the cognitive and emotional/behavioral domains. I was actively engaged in developing professional development support for classroom and special education teachers and helped develop and implement a special program for emotionally handicapped and behaviorally challenged students.

although I have taken many classes in the autism field, I feel that with each student, I need to review skills and practice the skills/ area of training.

I use videos in my classroom to reinforce information taught in class

Social Skill Groups and interventions

please note that there is no current, peer reviewed medical literature supporting the efficacy of sensory integration or facilitated communication, and these techniques should not be considered in the same league as treatments that are well documented to be efficacious in the medical literature, such as DTL and ABA.

Social Skills (Skill Streaming) --High level on training and used constantly

I had to advocate for myself to get an ASD workshop paid for and even that workshop was geared towards MH workers and /or teachers for ASD children. Eventually this population will mature and there are inadequate services for adult ASD population.

ILAUGH Model- Michelle Winner Mel Levine model

Dialectical Behavior Therapy - extensive training and use.

High level of training around Behavior Modification techniques

functional skills training and adaptations for personal safety, self care, posture and mobility, adaptive equipment

Facilitated communication The "Patience" approach (my invention)

34. What do you think would be effective in increasing the number of trained professional working with persons with ASD in Vermont?

Comments:

Trainings need to happen at a time when staff can take advantage of them and school systems need to support staff in summer learning, time off and paying for trainings.

In my opinion there needs to be a coordinated plan that helps us know what is working for each segment of the population, who is doing what, and how to do it. The comments about work load and salary make no difference in our agency--- we need more support to implement things.

training on providing family support services in the home environment, motivational interviewing, communication and listening skills, teaming and collaboration

Cross disability training open to all who serve students with significant challenges.

The amount of paperwork required for students receiving special education services is astronomical, especially medicaid (related services logs). Additionally, the State of Vermont is constantly changing paperwork requirements. I would love more time to work with families and their children. If I did not complete paperwork at home, I would not be able to provide services for children during the day. Therefore, the case management time indicated on a child's IEP service page does not occur during the work day; I complete case management on my own time, in the evenings. I would like to repeat my earlier statement: I would love more time to work with families and their children!

Parent education to allow continuity with school program in home environment.

Specifically trained positions to work with that one population - counselors, case managers, respite

Commitment at the state and local level that supporting individuals with autism to have quality of life is a priority. People don't invest time and resources to educate themselves for a career that has no future.

In general the state needs a basic level of training for staff working in all schools in Vermont. Advanced level training is not relevant for most school personnel in the state currently because the basic level training is so lacking. Expecting people to attend optional training the end of June and at other difficult times in the year is not the most effective plan to ensure a basic level of understanding for a large number of school personnel. Advanced level training for a core group of Vermont trainers designated to train all schools is relevant and essential. Guaranteed access to all school personnel who want and need training must be achieved. This is easier to do if training is regionalized.

Sharing of local expertise across school districts.

Use of video conferencing or Interactive Television/etc for state (or some other approved) consultation team to provide support and learning environment for local teams in the progression from evaluation - initial assessment to planning outcomes, to deciding on strategies that are the most meaningful to the child and family to the choice of methods etc

I truly feel that we need a way to train more people (through active modeling with children) in identification and then how to work with children. If we ask people to get more certification it will take too long and too many \$ out of pocket. Those of us in the trenches should be sharing their expertise with others such as FITP, Pediatricians and Child care providers on a need be basis. I would love to have more time to do mentoring with others than I currently have. I feel I teach families

and providers "as we go" while in the midst of teaching, shuffling paperwork, and meeting state regs. As my grandfather used to say " It takes a village to raise a child"! This is what our school systems are lacking. We don't go out of the box much even if it's not working! When was the last time a pediatrician actually saw 2 year olds in a childcare setting or visited a preschool to see typical social behavior? When was the last time FITP people spent time with groups of children so they could see how they pretend with toys and explore materials? When was the last time childcare providers assessed individual children or attended a school meeting that may impact how the child they care for acts at their sight after school? I know we all have our niche but when we have time to collaborate and talk about kids we can learn so much from each other!!!!!!! I also feel being paid for the effort and knowledge is crucial to keeping "good" people in all these areas! Not asking more from us and giving less time, resources and \$.

Many of the items listed above seem to be things that would keep people in the profession, rather than attracting them to it.

Regular team meetings that include all parties, including consultants, if necessary, on individual children.

Scholarships for professional when the school district can't or won't pay so that educators do not have to pay out of pocket

Case manager and job coaches would be very helpful for these folks.

All training seems focused to children with ASD; once folks become adults, any sort of innovative approaches seem to go away.

As I've had only one student with ASD in four year, it makes sense to offer professional development to individual who work with these students more often. When I have a student with ASD, they can (as they have in the past) work in close contact with me when I have such a student. As for the specific training my special colleagues have had, I don't know.

Again, training provided should be for techniques that have been demonstrated to be efficacious in current, peer reviewed medical literature. I see lots of training available for spurious techniques that have no research base. Vulnerable families and caregivers grasp at anything that will help their child; but I see time, energy and funding wasted on training and performance of techniques that have not stood the test of the scientific method and review process. This is very sad, given limited resources.

The model we are using is thus: We have a consulting teacher (that's me) who is being mentored (for five years now) by Linda Mulley and Chris Knippenberg on a monthly basis. This has been an amazing opportunity. I have been taking the collaborative courses on autism. The schedule and cost of these have been very helpful. I go to the schools to consult with the older kids and Chris and Linda now help with the little ones now that my skills are stronger and the EEE kids are greater in number. Besides the fortune that I have in mentoring with Chris and Linda, the best, most immediate jump in growth and the most applicable training I

have had was the TEACCH Level I training that was held in Bennington in 2004. This should return every three or so years. I would like to see this much more affordable and accessible. I am attending TEACCH II in January. What is frustrating is getting funding for paraprofessionals to attend trainings. The way our district works, we have to shell out the money in advance for training and then we get reimbursed. This puts many of the high-level training opportunities out of the reach of paraprofessionals. Also, it is hard to get training time with paraprofessionals and even for ourselves sometimes. It would be nice if there could be training in TEACCH, Verbal Behavior, Discrete Trials, etc. in the summer of just before school starts with grants support to allow districts to send teams at a less expensive rate.

On site training should include paraprofessionals. They should also be included in salary stipends or increases based on intensity of their students and high level of skills needed.

Don't forget to include the regular ed teachers too...one of the issues in our own district is working on making special ed and regular ed a better partnership...

In the last several years, I have worked with at least eight individuals on the autism spectrum, including Asperger' Syndrome. No two have been alike. It has worked best to get to know the student and custom fit plans and training.

More in school time for onsite training is counterproductive and disruptive to routines. Off site or web based helps immensely in terms of focus and fluidity.

District wide/area wide plan of ongoing training opportunities as staff are hired. Identify staff that will be working with the child with ASD ahead of the time that they actually start working with them.

Since every child and family is unique, individualized support for providers.

Training in collaborative teaming practices, VTs system of services and resources and training for providers related to working as partners with families as they prioritize their goals for their family member with ASD.

I think an overwhelming amount of emphasis has been placed on the "new epidemic" of students on the spectrum. Certainly, these students have unique needs as do all students with intensive needs. However we can not lose sight of the need to include them as much as possible into our school system. In order to accomplish this goal, we must constantly look at what they need to part of the community (behavioral and communication skills). Too often, it seems parents and professionals "relish" the disability, thus making (allowing) the student to be more disabled than they need to be. Definitely, professionals need support and assistance working with students on the spectrum. I think most school systems have the expertise they need in their school/districts to meet student needs. The time to collaborate is what's lacking. Going away to a conference to learn even more information you don't have time to implement, is a waste of time!

The only way training during work hours would be effective is if we can find

qualified substitutes so these people can be away from students. I'd put availability of trained substitutes on this list somewhere.

I can not stress enough, the one factor that is impacting the quality of support is the on-going increase of paperwork - let alone that the forms/paperwork do not stay consistent from year-to year. Although caseloads are on the rise I find it is the pieces of paper that is effecting my peace of mind.

more money and prestige proof of success

One key aspect of trainings is that they need to be more advanced and more specific to a particular method. I have gone to many introductory trainings about different aspects of Autism. More intense/higher level training is needed.

the challenges here are 1. there are no, zero, services available through our mental health agency for this population, a mandate must be made not just to DOE but to AHS for this population 2. parents want a cure instead of FAPE 3. lack of time, too many mandates from DOE, too much paperwork, too many changes every year to procedures and paperwork, announcement of changes delivered too late, we start the year behind and never catch up

36. What methods would be most effective for establishing trained professional to work with individuals with ASD? Comments

If you area going to provide trainer models with individual expertise, you should give accreditation to those participating.

It is all for naught, when regular education instruction is fragmented-every teacher is a kingdom in VT. Systems for meeting individual student instructional needs are best designed in support of a strong core curriculum. There is no such thing in VT. The education in Burlington metro area is a completely different thing than in rural and especially border Vermont. It is segregation to opportunity by geography-unexamined, because it is not flagged by obvious issues like language and color. Certification is only good, if it is broad so it meets the need of that individual autistic student and can not be "he is so happy", "she had so much fun". That is popular and attention getting for the staff, but shorts the student in long term life outcomes.

Including Individuals with ASD in the training and certification process.

I have been to many trainings on ASD and little helps in my day to day work. Each child is very different which makes it hard to coordinate services and treat them with groups, etc.

Actually working with ASD individual in conjunction with a professional would be the most helpful method

Specific program - cross between mental health and developmental services or a branch of developmental services.

Need to establish what is working and where you have success at the base level... find your true autistics (many are mis-labeled) and find where you have successful placement (happy, healthy and secure). These placements will tell you where your true professionals are. Those who are walking the walk,,, not talking the talk. There are individuals throughout the state who have been working with autism for years... they can tell you what they have learned over sometimes decades of research... trial and error. Training in isolation is useless. It is a hands on approach that one has or doesn't...

Not everyone wants to take classes and do unnecessary homework.

I believe there already are courses and BA's in place for asd training - they need to be well advertised and in combination with an improvement in compensation and working conditions. One without the other won't last long... Regarding distance learning - think it needs to be combined with some face to face time and demonstrations of what a good/useful assessment process looks like and how it is well used in an ongoing manner.

(see above) I guess the other suggestion I would have is to provide coursework for undergraduates that gives specific information about ASD and the characteristics of, as well as other common disabilities found in schools and preschools. I would also suggest more common training opportunities for Headstart, people college students and educators. I would also suggest more time be spent in childcare settings, schools and preschools for those going into education while in college.

Same comment as above--I don't see these suggestions as things that would increase professional involvement, although they would clearly enhance it for those already involved.

I would also add a low cost for the course- sometimes it hard to pay for the course first, and then get reimbursed through the LSB

Creating regional learning communities to create an exchange process would work best.

Provide intensive workshops for professionals and paraprofessionals

Mentoring programs should be staffed by professionals who will do more than drop "this is what you should do" in your lap. They should have the time and inclination to be hands-on, not adding something new to their administrative resume.

Cross training would be wonderful. Many of the teaching strategies used with individuals with ASD are not only used with ASD individuals.

I assume these trained professional would not be general education teachers as well.

Developmental Division specializes in this population yet they are not required to provide training or share their expertise to other divisions. This is unacceptable.

Make sure to allow professional who have had extensive training in the past to apply these credits and expertise into certification/licensure

Increased opportunities for on-going training across disciplines (e.g mental health , Family Services (DCF) and education)

feel that hands-on local support in work-environment would be best

The families and individuals will know best what they need, be sure to listen to them. Then remember that "most" people will be served well by any system you create, so leave a lot of flexibility in the programs to work with the ones that don't get served by the system you do create. That way all will be served as they need.

Training should be in research validated models.

Training in evidence based interventions, or strategies for building evidence, for specific interventions for specific children is needed- generally good teaching practices related to program development, identification of goals, instruction, accommodations and data based decision making. I don't know where to put this, but I think decisions about development of a system to support persons with ASD and their families is not necessarily a democratic process. Getting the most votes for a particular strategy or intervention may not reflect the growing research knowledge about best practices. Decision makers at the state level should review existing efficacy data as they develop programs, ask key questions relevant to Vermont, and decide how to answer them through data collection and monitoring. It will take awhile to figure out the most promising approaches. Diversity of strategies and options for families and individuals are important at this point. There's no one right answer.

Creating a certification will simply limit access to trained individual and create a barrier for parents who already think schools can't do this work. We need the mentoring and support, not the certification.

Training to parents on how to work with their school systems and how to implement suggestions school personnel provides. Most school systems, I believe, have staff/team members who have the experience needed to provide sound instructional strategies. Again the school's role is to provide the basic skills necessary for learning. In the case of students with ASD, social and communication skills may need to be firmly in place prior to the intense focus on academics.

My experience with "train the trainer" models is that the one trained never really feels sufficiently qualified to take over and/or they leave the district. Funding support is another effective way to increase trained professionals. The programs have to be easily accessible to all parts of the State.

I am not so certain it is the establishment of trained professionals that should be the only concern but rather the turn-over rate of trained support. My guess is that

families/schools will reply that they do not have the level of support that they need/desire. What I find is that people will stay for a period of time and then move on. This requires the cycle to restart once again- which in turn becomes exhausting for the trainers (family and school). I'm not sure how one would prevent this cycle - it's not just a \$ issue.

An effective program will include both "academic" and practicum components.

I would like to see either VSC or UVM take on a larger training role, similar to Division TEACCH at UNC Chapel Hill. Funding Bryan Dague and others to get more intensive training would be great. I think we can replicate some of their best practice. The supported employment outcomes from TEACCH are outstanding, 95%. I think our DD Supported Employment staff and VocRehab Vermont have much they can learn from the TEACCH model. Mental Health supported employment program went through a similar transformation when they began using a fidelity scale to rate evidence based practices for that population. Having staff devoted to supporting this throughout the state was crucial.

37. What are barriers to appropriate living arrangements for adults with ASD? Comments:

Lack of mentored and coached employment opportunities Lack of interactive, age appropriate social thinking, social skills training

Non congregate residential laws. Little or no training to generalize and train students with ASD toward independence and life after school. Dismal job and transportation in rural areas to make those options available to students with ASD. Meaningless training and activities.

With individuals with Asperger's there is little available---more for autism.

we are going to see a tsunami of people needing housing w/asd

Lack of providers who are skilled or who are willing and/or able to become skilled

There is a need for more small group living situations that would provide support and foster independent living skills for groups of 3 - 5 individuals.

Lack of direction at the State level in prioritizing individuals with ASD. Current trends seem to be that diagnoses by qualified, trained professionals are being second guessed by those who are untrained in this field, holding up needed resources.

Lack of knowledge of programs available to families with individuals with ASD or other special needs within the state of Vermont.

Funding should be directed to individuals who work directly with people with autism, and to those who are having success... There needs to be clearer diagnosis as there are many mis-diagnosed autistics,,, thus funding would be

directed away from true autistics...

What I see in most cases is that parents are supportive of their young adults post high school for a period of time and then the parents just seem to "burn out". I think parents tire of trying to keep their children organized and motivated. In some instances parents are trying to oversee their children who are living independently but who are having a difficult time keeping their appointments, paying their bills on time and otherwise maintaining a household that is clean and appropriate to live in.

I have limited experience with this, but the transition to a supervised/supportive living situation is HUGE for many adults with autism. Many schools do limited services in the home or in a simulated living situation so there is not the opportunity for a slow, planned, step by step transition.

Not aware of these issues for adults w/ASD. However for children I imagine a number of these issues are out there if the child doesn't have a clear diagnosis, and the family home doesn't have the where with all to manage the child's issues on a consistent daily basis.

Lack of affordable supported living arrangements that would allow these folks to live independently is huge.

Lack of knowledge of what is available for living arrangements

Basic living skills are not being taught. This is a chronic problem. People are graduating high school at age 22 with no idea how to perform daily life tasks.

HOUSING

Lack of adequate education on what would be the best option for both the individual with ASD and their families; lack of residential housing options.

Lack of overlap in services to support smooth transition, cross-training, and expanded services when students are in the last two years of high school. There is always a fight about getting agencies involved until the 11th hour. Even when involved, we have experienced broken promises and sabotage by agencies who made promises to have their teams shadow what we are doing for cross training and then simply failed to show up. A student with an AAC device he was able to use quite well who had developed some skills in community access, domestic skills such as cooking and cleaning, was reduced to a shadow within a year of graduation. No AAC device, following someone on errands. Training and adequate pay to draw and keep trained people is lacking in the human services and adult services arenas. In this area, several of the individuals who are working with adults with disabilities are running their own errands with the "client" in tow.

For older adults with an ASD it can also be the family is connected with the right resources. That may be changing as schools have increased their identification of ASD children. The first step is really identifying the families and connections them with supports. I also think the current lack of funding makes it difficult for people with ASD to connect with services when they are not accepted into

services because their 'adaptive functioning' is too high. These are people who regardless of adaptive functioning are incredibly socially isolated because of their disability and I believe it's important to help facilitate their social connection either through living arrangements or other structured activities.

Many adults with ASD cannot live with their families forever and yet most group home models are not appropriate. Specialized residential facilities/arrangements that offer targeted intervention rather than respite, tailored to adult needs and challenges are needed in Vermont.

Not sure on the financial end of things. One area of difficulty in general is treating the adult with autism as an adult with adult needs and their inherent risk- for family members.

A lot of resources for only a few...need to make funds and programs uniform across the state

lack of trained providers

no knowledge base

Lack of participation from any agency other than schools.

All of the above and transportation barriers/costs

Lack of understanding of the diagnosis of ASD - and the support needs.

Lack of affordable housing.

There is VERY limited funding and resources to provide such services for kids!!! Why just ask about adults? Research shows that if effective interventions occur early, skill development can be significant and ultimately reduce the need for more costly and longer-term services. Prioritize kids for effective ASD interventions by the appropriate providers!!

There is a lack of funding for adults with ASD and lack of housing available.

need more and different options than traditional DH type model for people with ASD. Need options with support but more independence than DH model provides.

These are not at all different from barriers for all adults with disabilities.

I really think that we are so out of line when it comes to transition of students with autism from High School to Adult services. My experiences have not been good at all. The schools are preparing these students to graduate at the ages of 17 and 18, then there are no services available to them until they are 19. This could put students in a crisis situation because they have had wrap around services, then there is no support until they can qualify for developmental services. If students don't have social security it is very difficult to get health insurance, because the insurance system may be based on the parents income if the student is still living with them.

Some adults don't fit the criteria for eligibility or system of care priorities so don't get services.

Distance

38. Do you have suggestions for the preparation of individuals with ASD for living independently? Comments:

Planning needs to begin at a level earlier than near the end of High School. Support and consultation along with a MAPS program specific to ASD would be really helpful.

As a parent of an adolescent who will require an assisted living arrangement in the future, I am concerned at the lack of community support for employment possibilities, training, transportation and living arrangements. Ideally, I would like to see my daughter in a group supervised home setting, assisted by graduate students who are majoring in special ed., or related fields who can utilize their involvement with the residence as credit towards their degree programs.

scaffolded life skills instruction

Start transition planning early. Advocate for more funding on a state level. Offer training for professional working with the student and supporting him/her after school.

Functional living skills training; supported living situations established and supported collaboratively among schools, VR and DS. Friendship groups including ASD peers and others with shared activities.

Basic Literacy.

Boarding school in a house with trained staff, graduate students with financial incentives on UVM tuition--essentially a waive, 3-5 adults with ASD in a home within walking distance to parks, churches, recreation, shopping. Multi-dimensional teams that support this plan from age 8-10. What is essential to positive life outcomes for these students, not what is needed for a short term test.

That individuals with ASD are just that "individuals" and what works for one person may not work for another. What makes this so challenging is that each situation is unique and has its own set of challenges. There must be enough time, money, and resources to develop individual support systems that fit the person with sufficient follow-along services and technical assistance for people with ASD to live independently.

I think that each individual I see presents so differently that it is hard to generalize with these questions. I work with a 16 year old who is college bound and learning to drive, but so passive that he may not be successful. I work with another 16 year old who is going to need supportive services for the rest of his life---he is being taught independent living skills, but cannot remember multi step

directions and misinterprets most things around him. Both sets of parents are very worried. Both sets are dealing with sexuality and dating (or wanting to). Little will be available for the first boy, but the second will likely qualify for services through CAP. As kids on my caseload become teenagers, they are more aware of their disability, but there is little out there to help them---jobs coaches, driving coaches, dating coaches (!), and help dealing with the reactions of others. A girl I work with is being taunted at school because of her Asperger's symptoms and she is emotionally fragile as a result. She seems to need someone to stop the bullying so she can grow and mature. Again, I believe that each individual is so different, trying to generalize with these questions is more frustrating than delivering the service.

Work w/the community at large to teach the general population that people w/ASD are valuable members of society who have plenty to give and teach; that people w/ASD are capable of learning and flourishing. This training needs to focus on parents, educators and others who support people w/ASD. my experience w/parents of adults has been somewhat negative in that their expectations for their adult child w/ASD are quite low. Perhaps this is changing. Early intensive intervention will also assist w/this goal.

Start at the youngest possible age with lots of intervention and exposure to social situations with the real world.

Needed funding sources for family support components to existing autism programs.

Creating more opportunities for schools to provide vocational training and independent living skills before graduation

focusing on the strengths of that individual rather than guessing at what they may be good at

Facilitated work arrangements beginning in middle school with curriculum centered on skills necessary to achieve post-secondary school success. Collaboration with state and national organizations and partnerships with college/university to set up transitional programs.

Independent living preparation is all so individualized, but should be determined by education teams. I believe independent living skills should be included in daily curriculum and schedule with, ideally, a facility in the neighborhood which would provide "simulation" opportunity.

Preparation and training needs to begin much earlier than high school. Teach life skills needed at an earlier age and reinforce their importance to life after high school.

Not a group home but perhaps a place where two or three folks could live together in a home with paid staff to assist them. I don't believe putting them into a place on their own with paid staff is the best because they are alone, except for the paid staff. It would be good for them to have peers.

Again, experience trumps education here... familiarity and trust trumps training

and programs. This is where true success lies and where if your concern is genuine, your funding will be most helpful to those who serve this population.

I think schools should look like places that will be used later-- houses (bedroom, dining room, etc) and work places -- more experiences off campus (stores, cafes, laundry, etc).

I am an occupational therapist and I feel that the ASD population is not adequately prepared for the transition into adulthood from high school. I think that transition planning should be started prior to the "super senior" year for these children. They should have access to vocation and to activities of daily living skills training in elementary school. I sometimes disagree that these children are pushed to do academic things and that the basic life skills are on hold until high school. Their programs should focus on life skills training from an early age so that they have time to learn these skills. If students had more life skills it may help them to be placed in a group home or community placement.

1.) Have a review of the Adolescent Autonomy Checklist at IEP meetings early in a child's high school years (or before). Integrate some teaching and practice of these skills either at home or at school if possible. If not practical during the regular school year, do this as part of a summer program. 2.) Expand the idea of a summer program for some type of statewide "summer camp" that would focus on all components of transition (employment, community connections, post-sec. ed. and independent living) and specifically addressing skills needed for home life, practicing social stories and developing peer networks.

focus on opportunities to develop independent skills throughout each individual's school career by providing the supports that enable them to be as independent as possible

-same as for my own son (listed above) -really determine at an early age if the school curriculum really will meet their needs as adults -more opportunities for community exposure at a very young age -more opportunities with recreational/leisure experiences ***starting young and developing these skills slowly over the span of school years (use the model of areas assessed on COACH to develop these skills) ***I recently have had opportunities to view autistic individuals whom I supported all through their K-6 grade years. I worked hard to support them in their regular classrooms and with the regular school curriculum. Without exception, these students remain atypical and look and act more "autistic" than they did in elementary school. Was what I was doing to "normalize" them actually making them more atypical? I think so!!!

Training of community resources, including police and fire and business..

Start teaching life skills early such as Jr. High. Involve individuals in the community they will most likely live in so they are acclimated and feel a sense of

community. Find 1 or 2 interests that will help be a constant for them as they are transitioning to living independently.

Training in social skills and life skills and job skills.

Not at this time - don't know enough about the specific issues. I would imagine a significant amount of structure in a small group setting with like peers might be appropriate, where there would be coaches and individual mentors living with the adults. I can not envision any of the ASD individuals I have known as children, living alone and independently, as adults.

We need case managers, job coaches and supported living arrangements for individuals with ASD. We also need to educate the public and the corporate structures about the benefits of employing these individuals.

Training on how to follow a schedule independently, completion of a checklist for tasks, safety skill education (how to use a cell phone & call for help, street crossing, cooking, etc.), transportation skills (how to ride a bus independently, bus routes to& from work, store, restaurants, how to use a map, etc). Money skills (counting, making purchases, using the bank/ATM). Leisure skills (Going to the movies, renting a movie, going out to eat, mini golf, etc.) Interview and work skills (specific to site and general do's& don'ts). Independent living coach fades out prompting (from daily sessions gradually to weekly check-ins) on skills and encourages self-monitoring (completing checklists, using daily schedule, etc).

I am a part-time nurse in a new ASD program with the middle school aged students. I don't believe there are a lot of programs guided directly towards us. I'm learning through reading and OJT. It works. Thanks for asking all these questions to better their world!

Phase the independence in-start with ASD individuals living in small groups with support and transition to more independence.

I think any school district that has a significant number of individuals with ASD who will eventually require assisted living support, should have a standards-based curriculum and a mentoring professional on hand along with trained professionals in the community.

Early identification and subsequent skills training that begins as the child starts school so that once they are an adult they will already have some of the skill base needed for independent living. Also more support groups in the area for parents as well as groups for the children diagnosed. These groups should extend into adulthood so that the individual can maintain that sense of support.

Create specific goals in transitioning ASD and have a person implement those goals for them. (i.e. transportation, independent living, social, communication, etc)

Since most people seem to be staying in school until they are 22, the last year or so should focus on vocational and life skills. Quite often I've seen this last year of school be something of a wasted period of time.

More knowledge within the community of the need for such homes. This would encourage private donations that hopefully the state could match and homes could be built. Without stress on the need for such things and the opportunities it could provide to the community, then our community goes without.

Having one on one specialist work with them all throughout the school years. Start school to work themes as early as possible.

life skills training, peer group support, circle of friends, ID resources and how to access them

curriculum for life skills including enriched leisure skills curriculum for community transportation vocational training in own community family support - share resources funding for recreational/social options funding for ongoing staff training

Better transition from school age to adulthood. Perhaps starting this transition at age 13 not 18.

Better understanding of how well an individual with ASD might function; sometimes the idea of living independently is very limited.

Intervention should focus on attainment of functional life skills including social skills via the use of techniques that can be demonstrated to be effective via medical research and not anecdotal evidence.

See above. Maddening! I would like to see a cooperative effort between agencies and schools to set up an independent living home for two to three individuals. Students still in school could access the apartment during the day to practice life skills. In the last year of school, when appropriate, the student could live in the supported living situation and would get support from the school during the day to learn to live independently in THAT situation.

Start early!!

Some people can never live on their own. For those that might accomplish assisted living perhaps timed trials and bridges to the assisted living situation.

begin life skills training as early as possible, well before preparing to transition out of school (elementary grades for basic life skills, middle school for higher function tasks (budget, shopping, safety in the community, communication with persons who may not be aware they have asd, etc)

strong aba program from start to finish. seamless services from education to adulthood encompassing community based residential opportunities.

Incentive programs for United Way volunteers or community mentor grants available for adults with ASD to live independently through daily 1:1 support

I think working with parents and supported living providers to help them let their children begin to individuate can be very helpful. The skills, cooking, cleaning, etc are important, and having the family support can really help for the

independent living situation to be successful. It's very hard for parents who've had to protect and advocate for their children for so long to let go and let their child individuate, so it's important to support them too.

In my experience, family relationship-based intervention at the earliest possible age is the best preparation for independent living and quality of life in adulthood.

Education related to self advocacy that involves the client and significant others with follow-up and reinforcement.

Start early with independence skills - teach and support independence in school and community settings from a very early age - requires teaching and supporting the community as well as the target child.

1) There needs to be a clear focus in school on developing the social-thinking skills necessary to function in the workplace. If students (and this isn't just about autism, here) leave school with academic skills, but can't work with other people, they aren't going to get or keep jobs. 2) Transition plans in high school need to be developed by age 16 at the latest, and need to be concrete and include social skills--actual work on the skills needed to get and keep a job. Voc Rehab and any other agency involved from outside the school need to be equally responsible partners in this process, and all parties involved need the funding and trained personnel to do the job that needs to be done to prepare our children/students to live independently.

Beginning early in childhood having the children learn how to live in other households. It de-sensitizes them to new surrounding and people.

Better planning and team work prior to the transition from high school. The transition times for kids with ASD are SO challenging, they need to be planned out in a mindful manner over time, so that the child is fully supported and the family feels supported.

Support, support, support...prepare them for what is coming up around the corner...provide answers to their questions.

As individuals with ASD often exhibit difficulty with change and as graduation from high school is often a very large change for these individuals, it is extremely important that transitioning to adult life begin early and that ample opportunity be given to lower anxiety.

Increased funding for independent life skills training, increased supported work opportunities, and over-all increased budgeting to support individuals across home and community settings

Because self-image and self-esteem issues are such a problem, all leading to risk of exploitation, preparation of individuals with ASD needs to include training in emotion regulation and interpersonal effectiveness, at the least.

Start working with transition age youth while in high school to learn independent living skills. Hook people up with their non-disabled peers.

Before the age of 22, school and home providers should be aware of what the adult goal is for this person. Having this awareness, schools and home can decipher goals to be around the future within their last school years. An overarching goal of living independently would apply to school and what their goals should entail, however most schools don't agree with this.

Early effective interventions (e.g. children's services) by trained professionals that are accessible in all areas of the state. Coordinate services with a clearly identified lead provider. Provide dollars and resources for thoughtful and thorough program development. Listen to clinical experts as well as parents.

The schools should spend more time working on independent living skills. Keep individuals in a school program until 22, even if enough credits to graduate. Allow that time to learn as much personal skills as possible. Don't just push them out because they have the credits to graduate.

Gear GLE's more toward independent living skills at the elementary level. These life skills are essential.

Developing independent skills for individuals with ASD within community, home and work environments prior to graduation. Determining appropriate levels of support for this independence and have the funding available in adult services.

more thoughtful transitions and continuity between youth and family and developmental services.

We need to look at co-housing opportunities that allow adults to live as independently as possible.

Group work, time - connections with schools prior to the individuals leaving. Connections with families on how to support independence - grouping families.

more focus on life skills in schools and immediately upon graduation.

Spearhead a social skills curriculum for ASD kids. Provide funding for ESY and make SS a basic skill area.

Start early building functional independence in their context.

Assuming we keep in mind the tremendous range of abilities in this disability category, I believe it's crucial to tell children early on about their disability (almost always preferably by the parents or guardians and reinforced by others throughout their lives) and why certain things are easy for them and certain others difficult for them. If they are verbal, people with this label need to become as well-versed in it and comfortable with it as they possibly can. There's no surer way to keep a person dependent and child like than to keep this information about them from them as if it were too sad or too complicated to share with them. Parents and others who work and play with people with ASD need training in this very delicate yet very vital endeavor.

Teach others in the community about how to interact and befriend people with asd. Teaching others to live and work with individuals with asd is as important, if not more important, than increasing the skills of people with asd.

Have independence and competence as core skills from the start of intervention--keeping the long-term goal to be maximizing adaptability and skills for independent living. Raising the level of training and expectation for occupational therapists as one group of professionals who already have a solid background in independent living skills--using them for mentoring and supporting home-based/community based activities, assuming that they have advance level training and some semi-standardized decision-making systems to support their work.

life skills training, social skills groups, self advocacy training, work environment social skills training

A lot more access to the community in which they will be spending their time after completing public school. Practice using communication methods in the environments they will have access to. Preparing them to access community services, recreational opportunities and worksites. Begin early (even in elementary school) and PLAN, PLAN, PLAN!

I believe families need on-going family counseling from the minute there is a diagnosis. I don't believe support groups, advocates or chat sites are sufficient. There needs to be a professional meeting with families and checking in with parents and siblings.

start from the bottom and build homes for peer/foster parents that meet needs of both.

Alternative residential models post high school that concentrate on social skill and community access development.

Have different independent living and learning sites run and managed by educated professionals. Make the individuals test out of the houses. They would live there until they can apply the independent living skills to a certain high standard. Once they move out on their own then they can be monitored for a period of time.

I think there should be a transitional living program for students. I meet with families that are feeling so overwhelmed and tired when their student is at the age of 18 or older. I don't think they know what the next steps are and it has to be very difficult.

The information at the TEACCH conference offered suggestions for alternative living arrangements as well as supported employment that we need to implement in Vermont. The trained staff that were described and seen in the film that was shown are above the level currently available in Vermont. Also supports in the

working community are described that would be advantageous to programming in Vermont.

Let families know that the pace of building independence is set by the individual and that they need to take an active role in helping. Adult services are not an entitlement.

More focus on teaching towards independence in daily routines, social communication skills and relationship building and less attention to compliance training. Opportunities to be included in natural school and community activities and settings with appropriate supports and less focus on separate programs and settings.

put mandates on mental health, they get a lot of our tax dollars with no accountability and the services are limited to non existent

Start early in educational career. Use personal care workers to train independent living skills. Training in job, independent living and social skills while still in high school. More intensive supports available through both VR and DS systems.