

Attachment E

Children's Creative Connection (C3)

Needs Assessment Survey - Results

July 2007

Results of the Children's Personal Care Services Survey July 2007

Total Survey's Returned = 494

General comments indicate a comment related directly to the question (written in by participant). If more than one recipient made the same or similar comment, each was kept in order to show the number of like comments for each question.

1) Child's Primary Diagnosis Identified As:

Primary Diagnosis	Count	% of Total
Autism Spectrum Disorder	155	31.44%
Developmental Disability (other than Autism)	95	19.27%
Mental Health Condition	24	4.87%
More than one disability	188	38.13%
Physical Disability or Health Condition	31	6.29%

General Comments:

still trying to get an accurate diagnosis

2) Currently employ own children's personal care workers:

Employ PC Worker	Count	% of Total
No	36	7.29%
No Answer	8	1.62%
Yes	450	91.09%

General Comments:

Respite through ARIS
through PCA program
Can't find any daycare!

3) Use all or nearly all allocated hours of care:

Use Hours Allocated	Count	% of Total
No	159	32.19%
No Answer	11	2.23%
Yes	324	65.59%

General Comments:

But will use more due to new divorce and becoming a single mom
cannot find someone
Can't always find PCAs
depending if I can keep workers
Depends on time of year, burn through most during summer

Difficulty finding caregivers independently and agencies unable to fill hours.
Every other week we get all the hours, the other week we only get half the hours.
Hard to find caregivers
I want more hours! We need to pay these PCA's a higher rate. They need ongoing training and supervision from licensed therapists. The way the system is set up now is like giving a drowning child a chair. I consider it to meet the definition (legally) of abandonment and neglect.
I will on the next 6 months – summer
Just found a worker right before the 6 month review.
My PCA was sick and then moved
nearly all but always have some left
no - due to the rate of pay for this job
no - wish I could "rollover" unused hours, I could use them over the summer/next 6 months
no in winter - yes in summer
No, due to worker not available, conflict of schedules, etc.
Not enough PCAs to fill needed hours
Not sure - just started
Not sure
Only because we cannot hire reliable assistance. Great idea!
She is currently able to attend school with a modified schedule.
sometimes we do not have a person to cover hours
Sometimes
sometimes, mostly in the
We love if this plan was in place
We usually fall short of using all our allotted hours during the school year but need more hours during vacations and summer break when the children are home from school
We will over the summer months. This is our first six months of PCS.
When care is available
Worker not available, conflict of workers schedule, etc.

4) If flexible option were offered, would take advantage of it:

Take Flexible Option	Count	% of Total
No	52	10.55%
No Answer	28	5.68%
Yes	413	83.77%

General Comments:

possibly
Yes and No PCAs need to be acknowledged and treated like the rest of the working world..they need incentives, cost of living increases, benefits, etc. "like the rest of the working world" so we as families can keep them interested in their deserving work!!
Absolutely, for transportation and to up wages.
Possibly 6. Maybe 7. Somewhat
Maybe
Absolutely - I think this is a very respectful way to offer services to kids with special needs. Some families, however,

will need more assistance than others to best utilize this benefit for their children
As long as it did not interfere with the hours that we use for personal care. 6. Maybe
Don't know - maybe 7. Need more information as to what I could do with it.
Don't understand why VT won't pay parents 40 hrs/week at \$10.00/hr to care for their own child. Other states do. (AL) Problem w/care attendants is they don't always show up and the parent has to stay home anyway and lose their jobs. I feel that VT should look into this option also. It would help a lot of parents with special needs children.
Don't you worry of folks taking advantage?
I think I might depending on what it could be used for
I think so
I'm happy knowing the funds are there to help care for my child, who knows what will be needed down the road
Maybe
Maybe
Maybe
Maybe
Need answers before I could say. From what I can see yes, As long as I can track it like my respite budgets
Not sure
Not sure
Not sure
Not sure - a few questions - taxes? Advantages?
Not sure yet
Not sure, We would want to use most of the \$ for care time, but would like to get some equipment or therapy. But we only want to do this split if the payroll continues to be managed, ie some one else does the SS & taxes.
Paying my worker and maintaining yet more records to report would be a burden. Doing background checks would be complex and many families probably wouldn't do them...
Probably, but would have to weigh against what we currently receive, how much administrative red tape would be involved? Our budget already stretched to limit, ultimate solution will involve greater funding. Despite this and other medicaid funding my adult son's program is heavily dependent on parental funding and personal support from parents.
Too many people would abuse it!
Unknown

4a) Why would not use flexible option if offered:

No Flexible Option Reason	Count	% of Total
Can't think of anything I would use it for	4	7.41%
Happy with what I have	24	44.44%
Too complicated	6	11.11%
Worried I would lose hours	20	37.04%

4a. Would use if available but worried I would lose hours

General Comments:

No Flexible Option	Other Description
	all of the above - worried I would lose financial support if allocated hrs were not used
	All of the reasons indicated
	assuming program is like current "self managed" would not have flexibility of coverage when main caregiver is out

Can't think of anything I would use it for
Can't think of anything I would use it for - Worried I would lose hours
Child needs the personal 1:1 and social skills, but would be nice to know the flexible option is there if needed
Don't know
happy with ARIS payroll
happy with what I have
He needs a lot of of 1:1 social skills. He doesn't trust adults. He was abused by school staff. So he needs a lot of TLC
I think CSHN wouldn't cover the OT and I would have to use money for that service and it would leave very few hours left.
I would be afraid CSHN would cover occupational therapy and therefore would lose hours
I would not be pleased if this negatively impacted my son's SSI funding
I'm assuming I wouldn't lose any hours based on other sheet
My child's care giver works for professional nurses and can't work independently
Need more hours wiggle room
Needs the 1:1 social skills, needs to know someone cares beside mom. Really like the flexible option.
not enough hours
Not sure yet
PCA availability
PCA has been with him since he was 6 months old
Right now the 1:1 social skills is still working but in the future other things may have to be done.
sounds like it could be more to keep track of.
What difficulties are there documenting "other" services or items?
What if an emergency happens and you are out of hours and need to leave child with PCA
Worried I would lose hours
Would be too easy to mismanage
Would need it to be more "flexible" in my case
would take away the number of hours 1:1 care services
wouldn't have enough PCA hrs if used for other services

5) Flexible option used for: (could choose more than one)

		% of Total
Service_Coordination	69	3.20%
Community_Supports	251	11.63%
Respite	312	14.45%
Behavior_Interventionist	136	6.30%
NonMedicaid_Funded_Goods	225	10.42%
Mileage_For_Employees	232	10.75%
Traditional_Personal_Care_Services	278	12.88%
Advertising_For_Workers	83	3.84%
Training	167	7.74%
Higher_Pay_For_Workers	291	13.48%
Lower_Pay_For_Workers	13	0.60%
Other	102	4.72%
	2159	100.00%

General Comments:

Case management? Ha! As if your department employs anyone with even the most rudimental knowledge of ASL.

Why would we allocate money to a state government employee to tell us there's no services for our child! We need to be able to go out and recruit and pay our own therapists from out of state
non-medicaid funded - only at end of 6 month if left over \$/hrs
Non-Medicaid Funded - If we had extra month at the end of the 6 month period.
I would want this budget separate from my respite budget. Would timesheets still be done. How would that work?
pay your worker higher rate - Why can't my support agency (FF) have flexibility in deciding hourly wage?
non med goods - If needs came up this would be great
A number of these options would definitely improve the quality of her care and help her progress.
mileage - a couple of my PCAs have mentioned transportation costs are so high.
my daughter has personal care and respite, it is very important to her.
Pay worker higher wage - If I thought I was going to lose this person, I would offer her a raise because child trusts this person.
Pay worker less - silly suggestion
pay your worker less - this should not even be an option
respite - if only there were such a service
Respite - we are over income for FF.F Non-Medicaid Funded - possible alarm so we will know if child wanders

5a) If answer 'other' in 5 above, indicated as follows:

FO Other Description
bedrails, bumpers, door alarms, etc.
I like the respite and we need this bad
therapist (PDD) who is not covered by our insurance
camp for special needs - horse camp
specialized therapies ex. RDI
things to do in the community
yoga instructors/classes, music therapy
speech therapy at home
be able to use some for things to do with worker ie. Movie ticket, amusement park, Montshire museum. Would this be allowed?
job shadow/career counseling/Independent Life Skills Coach
behavioral program w/therapist not covered by my insurance
summer camp programs, membership @ fitness ctr to use pool for "body space" issues
specialized therapies
music lessons/movement/horseback riding/PT/OT/Speech, therapy toys, computer
non-covered therapies
help w/non-covered therapies
Partners in Adventure Day Camp
diagnostic/therapeutic services not covered by Medicaid
RDI
movement therapy to help with re-attachment to adoptive family
Purchase educational software and other materials and equipment
OT services or co-pay on such services
programs to increase my child's muscle tone - hippotherapy, swim lessons, massage, vision therapy
purchase specialized therapies and equipment that medicaid does not cover
other therapies
hippotherapy, adapted swim to keep range of motion

pay for camp Thorpe - 1 week in summer
therapy equipment therapy not covered by medical insurance, cost associated w/travel, meals, accommodations related to medical and therapy needs, medical bill not covered by insurance
specialized therapies
non- medicaid covered movement therapy for attachment issues
pay for other therapies not covered by insurance
just being able to have the chance to use it how you need it sometimes. Like changes and need
specialized services - social skills and communication skills
Camps
speech and IP therapy, vision therapy, OT/Hippo therapy
It would vary according to the most urgent need and situation.
membership to fitness ctr for access to aquatherapy, address gross motor, fitness level and support healthy lifestyle
Help w/ cost of extra food and supplements son needs.
Save up hours/money for extra hours of care during school vacations.
Get her to go to camp
Specialized Therapies
Other specialized care not covered - RDI consultant, etc.
Pay for services like swimming lessons that my daughter needs that medicaid won't pay for. She needs this to try to get stronger.
If allowed some of the best PCAs are under 18. (14-18) I have a cousin I'd like to employ but she is under age.
Social skill development- Asperger children constantly need to work on social skills, getting out of comfort zone, new people, new places, new skills, interpersonal skills. Take a class (art, music, drama) learn a job skill, life skill, cooking.
Development of social skills, Put child in environments where need to work on social, world, job related/employment, new, interpersonal skills,, ie camp, class during summer, Asperger kids don't like change, want to "hole up " in safe, comfortable places
Specialized therapies
Art and music classes for special education not funded by schools
Therapies not covered by insurance.
Swimming program`
child's transportation
pay two workers to care for child, access recreation, etc in community if I was unable to do so or so I could go to Montpelier for meetings, presentations, speakers, etc
Fees to get into events
Money for fun activities to cover both child and worker!
Money for fun and educational activities
Help make home safer for her with her seizures
Speech therapy
Educational materials
Social skills programs, Stern Ctr or Philo Ctr, very expensive if not subsidized and it is not covered by health insurance!!!
Services for social-like bowling, movies, fishing, and other social events to help him to interact better!
Pay for Silver Towers Camp -orthodontic \$5,600 braces, would have been nice, we just finished paying for them
Need a signing PCA, hard to get for \$10/hr
Money to take them to activities - museums, plays - to pay for both child and worker
Therapeutic activities
Therapeutic/adapted recreation - riding, swimming
Therapies not covered by Medicaid
Materials to help teach safety programs (swimming lessons, etc)
Special camps
Pay for RDI treatment/intervention
Speech/language specialist

Kids on the Move, occupational therapy
Autism advocate
Special activities for child w/ PCA
Transportation to and from school
Have employee go to IEP meetings or help with health appointments
Summer camp, therapeutic horseback riding, school paraprofessional
Karate/Tai lessons that are too costly
Speech therapy in summer when EEE doesn't cover it.
Purchase FM system for home

6) Would use flexibility to pay two CPCS workers to care for child at the same time:

Pay Two Workers	Count	% of Total
No	327	66.46%
No Answer	32	6.50%
Yes	133	27.03%

General Comments:

maybe
Possibly depending on the circumstances for ex. Gymnastics
ABA's & such - this would be great
Sometimes
mainly an occasional overlap to ensure continuity of care if I am unavailable (out of town)
Maybe
Not sure
Two workers are not needed for my child - however, might be for others. This is a fantastic idea that not only meets the special needs of my child (I would immediately choose pool and/or music therapy!) - but helps me keep employees - I can compete with the market place. PCS work is hard, employees need proper compensation.
Maybe
I think I might do that in some safety cases with my child it would be very helpful.
It would be helpful for training a new PCA but only at that time. A list of people who want to do PCA work would be very helpful.
How can 2 work at the same time?
yes - to manage playdates
Maybe in special circumstances I would pay 2 workers at the same time i.e. horse therapy
On occasion
At certain times, when 2 people are needed. This would be great!! It would give us so many more opportunities.
But only when training someone new
But possibly if situation changed
But the one more hours
Don't know This is a fabulous idea!
During training
for training new CPCs
I don't understand the question. Simultaneously? No Two different people at two different times, yes.
I would pay one more per hour.
If I could find people, I just lost one

If I need them to go to the hospital with me and help me with her.
if it came up/ sometimes there is an overlap
If needed, my son can have very challenging behaviors, he is a 2:1 at school.
In some situations
It would depend on the child I was using it for.
Maybe
Maybe
Maybe
Not sure
Not sure
Not sure why?
Occasionally, when I cannot accompany worker to an event in the community, as Lynn requires a 2 person lift for all transfers
6. On rare occasions (training, meetings, etc)
Only for training purposes.
Only in extremely limited circumstances, if allowed.
Possible - not sure
Possibly
Possibly
Probably not but if the need came up.
Sometimes
Somewhat
That is great for training new educational/play methods and on her rough days
To allow one PCA to train another PCA.
Unless for a training or special event? When more support is needed ie camping trip
when appropriate/needed if allowed
when training new staff
yes, so that one highly trained professional could train another PCA
I dream of the day when parents can be paid PCA hours, Working as a single mother with my son is the hardest struggle. 6. At times

7) Understand what this new option as described:

Understand_FO	CountOfUnderstand_FO	% of Total
No	26	5.28%
No Answer	23	4.67%
Yes	443	90.04%

General Comments:

in general
Kind of
Except the logistics This is an incredible idea! I hope it goes through!
I would like more detailed explanation of my child's rights!
Somewhat

Need more information as to what I could do with it.
Not completely
Not completely
Not completely.
Some
Partially, low would services be approved and authorized?
But would like more information
Some
Could be clearer but sounds like a great idea.
Mostly
Not all of it
Not completely. Would the monies still be managed by ARIS ie. Payroll, tax deductions, or it this lump sum distribution to us? We're not interested in managing tax deductions.
not fully
Somehow needs more clarification.
Somewhat
Somewhat
Somewhat
Somewhat I do
somewhat, but want more details
sort of
Somewhat
would like to talk it over with local case manager for myself
yes - I would look at the program options before I opt in
Yes and No

8) County of Residence:

County_of_Residence	CountOfCounty_of_Residence	% of Total
No County Listed	2	0.40%
Addison	29	5.87%
Bennington	47	9.51%
Caledonia	37	7.49%
Chittenden	110	22.27%
Essex	11	2.23%
Franklin	42	8.50%
Grand Isle	6	1.21%
Lamoille	17	3.44%
Orange	28	5.67%
Orleans	15	3.04%
Rutland	49	9.92%
Washington	38	7.69%
Windham	35	7.09%
Windsor	28	5.67%
	494	100.00%

GENERAL COMMENTS (not associated with a question #)

By having a flexible pay option I could get additional therapy for my daughter. This would include swimming, PT, speech and reading assistance. Also, paying our summer PCA a higher wage would be awesome!
Flexible spending of PCA hours would help, but not replace the need for the reopening of the Home and Community Based Waiver.
I dream of the day when parents can be paid PCA hours, Working as a single mother with my son is the hardest struggle.
I have a person who has work for us for 5 years at the same pay!
I like using the hours as is for a person to help her. I would like to use flex money for gas to take her places or mileage. I would like to use hours not used in the winter for summer time when school is out.
I really feel that this would enhance the PCS benefit for my son.
I think this is a great idea, however, I do have a concern that the legislature will pull other funds (like FFF) because they think this program covers it.
I think this is great but will Aris still do the billing I hope?
My son has Autism and several other problems but he loves to be stimulated by movement. It would be nice to have a swing set for him, but it would cost so much. I need something that can grow with him. They cost \$3,500.00 and how would that work in this program. Would we buy it and be reimbursed or what?
Not a lot of available camps that take a child w/special needs. Also, take a special child w/a PCA. What to do for working parents that can't afford the two, camp/PCA hours?
Phone line connected to another person
This is a wonderful idea, especially for school age children. It is hard to hire personal care workers for a couple of hours a day after school especially in rural settings.
This is so GREAT remember to use us parents as a resource
This new plan would much better meet my child's needs!
This would be great! I need equipment for my daughter that I cannot afford.
We home school and our local school system is not all that helpful.
We use all the hours, so we would still use the money for PCS, but we have many other expenses related to our son.
Would we have to do our own background checks and payroll?