

**FAMILY CENTERED
EARLY SUPPORTS AND SERVICES
FAMILY COST SHARE
PILOT
October 2013**

A select number of New Hampshire Families participating in Family Centered Early Supports and Services were asked to take part in a Family Cost Share Pilot. Each family was given information defining a family cost share, why it is being considered, and what the process and cost may look like should NH decide to implement a family cost share. Following this, each family was then asked to complete a short questionnaire. The results of this pilot project were reported to the New Hampshire Interagency Coordination Council on October 11, 2013

Background

The Family Cost Share Pilot was created by the New Hampshire Interagency Coordination Council (ICC) to explore the use of a Family Cost Share process as a possible way to help sustain the Family Centered Early Supports and Services (FC ESS) program. FC ESS has been level funded for the past five years and is dependent on Medicaid, private insurance and the Part C grant (Part C of the Individuals with Disability Education Improvement Act). State funds are used as the Medicaid match. The current funding is not sufficient to maintain the current FC ESS program and it relies heavily on additional funds provided by the Bureau of Developmental Services (BDS) to sustain it. A Family Cost Share is a possible funding source that has been used in New Hampshire in the past to help support FC ESS and is currently in use by many other states to support their programs. The ICC was encouraged by the agency responsible for administration of the program, BDS, to explore this option.



The ICC created a sub-committee to look at the possibility of charging families a fee. This sub-committee created guidelines based on the experiences of other states, New Hampshire's current costs and enrollments, and the commitment of the State of New Hampshire and the ICC to provide families with affordable, quality service. A Family Cost Share "packet" was created which contained the "Family Cost Share Financial Information Form", a "Chart of Monthly Payment", and a list of quick facts about what the process for a Family Cost Share might be and why it was being considered. It was the sub-committee's intent to find out from families connected to FC ESS how the process they developed worked in the real world, what might need to be changed and to collect family feedback.

Method

At an FC ESS Directors meeting in the spring of 2013, directors were asked if they would be willing to pilot the Family Cost Share with five families in their region. Volunteers were provided an envelope with 5 packets each that contained the Family Cost Share Financial Information Form, the Chart of Monthly Payment, the list of Quick Facts and a Family Question-

naire designed to solicit feedback from the family. They were specifically asked to approach families who would be new to FC ESS in an effort to obtain a more neutral opinion. The directors were asked to explain the Family Cost Share Pilot to the family and proceed with the process of collecting family financial information and calculating what the family cost share payment would be as if the program were in place. They were to share with the family that this was for information gathering only, private information such as name and address need not be given, the process would be completely anonymous, and that there was currently no family cost share. The intention of the pilot was to collect information about the possible process. The family was, however, to be instructed to fill out the form as if it were real in order to provide feedback on what it would be like to actually provide family financial information and provide feedback on the information they were given to explain a family cost share. The director, or their representative, was then to ask the family to fill out the Family Questionnaire or to fill it out with them, whichever the family preferred. Each questionnaire was subsequently placed in a sealed envelope in order to maintain confidentiality. The directors were also asked to fill out a Family Cost Share Pilot Evaluation in order to collect their feedback on the process. A total of 11 envelopes, each containing the five family packets, were distributed to Early Supports and Services. Of these, ten were returned which resulted in a total of 44 Family Questionnaires and 7 Family Cost Share Pilot Evaluations. The findings for each survey are provided in the appendices at the end of this report.

Summary

Based on the Family Questionnaire, it was clear that all families understood why finding a new funding source is necessary, and all families understood what was being proposed in the Family Cost Share Pilot. The FCS Pilot Evaluation also showed that most directors felt they were given enough information to explain the pilot and why a family cost share was being studied. It did seem, however, that some information was missing. Two directors answered no, they did not have enough information and wrote: “How would assistance be provided if they couldn't pay copay” and “Families wanted to know why EI would receive budget cuts when it is such an important program.” These concerns were also stated by parents, such as the comment “Will a wait list be instituted for families that can't afford to cost share?”

The details of the proposed Family Cost Share payments were mostly understood by families. Ninety-one percent responded yes they did understand how the family cost share would be calculated. Eighty-six percent thought the payment calculation chart was easy to understand and understood how much they would have to pay. There was feedback on how the form could be changed by perhaps adding a simple equation where someone could fill in totals from the Family Cost Share Financial Information Form to calculate the monthly payment, and by clarifying if income represented was gross or net.

In question six, families were asked if they were required to pay a cost share, would they still participate in Early Supports and Services. Seventy-seven percent said yes, they would. One person answered “no”, while twenty percent wrote they were uncertain; it would be questionable or depend on other factors, such as how their child was doing, the skill of the therapist or how many services their child was receiving. Eleven percent (five respondents) commented they were concerned about the cost and whether they could afford it. There were many (nine) positive comments as well with families noting how important FC ESS is and how well their child is doing.

Information was collected on the Family Cost Share Financial Information Form. Eighty-six percent said they understood the form, seven percent said they did not understand it and two people skipped the question. Comments showed there was confusion over different types of income sources and what should be included, and again, feedback was given on how to improve the form such as changing alignment and box sizes. Fifty-two percent stated that they did not struggle with the form and did not have trouble finding the information. Thirty percent made comments concerning difficulty in finding different pieces of information, such as premium costs and pay stubs. There was a suggestion for spouses to fill out the form together and other parents noted they were not the one that usually handled family finance. The directors reported that families, in general, did not mind sharing personal financial information although some of this was due to the anonymous nature of the pilot.

The time to complete the form varied considerably. Some people were able to find all the relevant information very quickly while others said it would take weeks. Five people commented they did not include finding the information in their answer on how long it took to fill out the form, just the time to write it out, and others noted that it took minutes because they were just guessing. Most families reported they were able to fill out the form in less than 30 minutes (75%).

Every family was given opportunity to ask questions or submit concerns. Question eight asked “What are three questions or concerns?” and question nine asked “Any additional comments?” There were 43 responses to these two questions, 10 of which indicated they had no questions. Others were concerned with how the calculation of the family cost share was made or what it included, such as: “Is it the same price no matter how many visits”, and “Should make it clear if expenses are for the entire family or just child being treated”. There were several comments with concerns that a family cost share might cause delays or prevent children from getting services such as “Would this prevent some people from getting services?” and “Will we be turned down if we can't pay copay? This was a concern in the FCS Pilot Evaluation as well where it was noted a family wanted to know how assistance would be provided if they couldn't pay copay. While there were many questions on the process of a family cost share, comments such as “I believe this is a beneficial program for my son and his development is extremely important” and “Well worth the money” showed many families value and understand the importance of Family Centered Early Supports and Services.

Recommendations

Should the ICC choose to move forward with a family cost share, families' questions and concerns indicate that more information needs to be provided at the point where the cost share is explained. Clear information on what the fee includes (i.e. when more than one child in a family participating) should be developed. Information on how a cost share would impact insurance - both public and private, and how the cost share payment is different from insurance co-pays would need to be explained. The people responsible for collecting family cost share information should be well trained in how to give information to families in a family centered way.

A Frequently Asked Question sheet could be created and routinely updated based on family questions.

The various forms should be revised to take into account some of the feedback families provided such as alignment of boxes and space for responses. Families should be allowed to take the information home and complete the forms on their own, in their own time and with the assistance of others. Families would need to be provided with a phone number of a person to call should they have questions. A self addressed stamp envelope should be included with the packet for information so it can be sent to the appropriate place.

It was clear from our sample that while most families, 77 %, responded that they would still participate in FC ESS, others were not so sure. If there is a Family Cost Share, some families may choose to not participate. It may be that these “maybes” did not clearly understand the how a family cost share might work and clarifying the information, as mentioned above, might reduce this number. However, it may still be that some families choose not to participate.



Findings

The responses to the Family Questionnaire are as follows:

Q1. Did you understand why finding new funding sources is necessary?

All 44 respondents (100%) answered yes.

Comments were:

- Coming from another program in another state where we paid a family share and we had more resources. We didn't mind to pay some to benefit. Looked at it as if we had to pay doctors it would be so much more.
- Understand funding is required
- Unfortunately, I understand it well!
- No more money in budget because of cuts possible in future
- Always cuts

Q2. Did you understand what is being proposed?

All 44 respondents (100%) answered they did understand what was being proposed.

Comments were:

- Well explained.

Q3. Did you understand how the family cost share will be calculated?

Forty respondents (91%) answered yes, three said no, and one wrote “a bit confusing”.

Other comments were

- Why are there two different pages?

Q4. Was the Payment Calculation Chart easy to understand?

Thirty-eight (86%) said yes, four said no and two replied “somewhat”.

Other comments were:

- Easy
- After explained a couple of times
- Unclear whether it was before tax or after tax, and whether it includes unearned

income

- It was confusing, didn't match, wasn't sure how to get to income number. Could put simple equation on chart.
- income net or gross? How are assets, expenses, and health insurance premiums included?
- I like the two demonstrations
- Yes- but not to all

Q5. Did you understand how much you would have to pay?

Thirty-eight (86%) said yes, five said no, one replied “somewhat”.

Other comments were

- \$30/month
- Seems if you don't hit that number on the chart, you don't pay.
- Unsure, see above
- Finances vary because job is contract
- There were two different costs, not sure which side was correct

Q6. If you were required to pay a cost share, would you still participate in Early Supports and Services?

Thirty-four (77%) said yes, one said no. Nine others wrote:

- Probably not. Cannot afford it
- Questionable
- Most likely not. It would depend in the skill of the therapist and the amount I would need to pay. If we were a 1st time ESS user, I wouldn't pay.
- It might depend on how my child is doing, but I would try my best to keep her in
- Maybe
- Probably not as I don't feel my child absolutely needs the services and don't know
- Depending on how many services- some people wouldn't be able to pay the fee that I would be willing to pay for services
- Probably

- I could justify the amount based on the amount of services he receives, but I don't know if he were only getting 1

Other comments were:

- Would be less than the copays per month
- I believe this is a beneficial program for my son and his development is extremely important
- Well worth the money
- It would only improve what is already a great program. It would be totally worth the cost share to have more resources.
- At the proposed rate, it seems very fair
- Yes!
- Would do everything in my power to pay for the services but it would be a financial hardship to our family.
- Yes but it would be difficult, would potentially need to get support from other family members.
- Now yes but my husband probably would have vetoed it when the idea was initially presented because 1) he didn't know how cool and helpful [ESS] is and 2) he didn't talk until he was about three y.o. so he didn't see what was problematic about D. not talking at 18 months
- Yes, how could I not for my child?
- My child needs and shows improvement.
- Absolutely.
- Yes, but we would want more services monthly because of cost share.
- The program wouldn't cost us anything 3 people, \$45,000
- It is really helping C.
- Would have to because would have no choice

Q7. Did you understand the Family Cost Share Financial Information Form?

Thirty-eight (86%) replied yes, three replied no, one “sort of” and two skipped the question.

Other comments were:

- But not at first
- Gross verses net, difficult for self-employed to figure net .
- Chart should say other expenses over court ordered support etc, should have its own section.
- Would this cost apply to the max out of pocket for medical insurance?

What did you struggle with?

Twenty two respondents (50%)stated no, nothing, n/a or 0, and three skipped the question.

Other comments were:

- Did not know what insurance premium was, estimated
- Would take more time than this visit allowed. As a self-employed, dad does not want to show income.
- Chart of monthly payment
- Insurance premiums paid per year. Not sure.
- Expenses
- Kids social security numbers would take a while to find, insurance cards are easier, but why would you need their address, unsure what premiums are per year.
- Before tax/after tax income, unclear what wages should be for one month (form talks about bi-weekly as well as one month)
- Address of insurance company not on card, premiums would have to be found unless you put look on paystub and figure it out
- Insurance payments, school loan payments
- Gathering my husband's tax papers, he is self employed
- Finding insurance expenses information
- I don't think the cost share form gives an accurate financial picture for our family. Many other bills were not factored in.
- Finding financial information
- Gathering the information because income varies greatly
- Finding all the information.
- The boxes are confusing. Should use lines or align things in a more clear manner.
- Health care? dental costs without looking at paystubs

- Coming up with what my premiums were and figuring all medical expenses--glasses are not always yearly.

Was it difficult to find the information needed to answer the questions?

Twenty-three (52%) said it was not difficult, three said yes it was. One skipped this question.

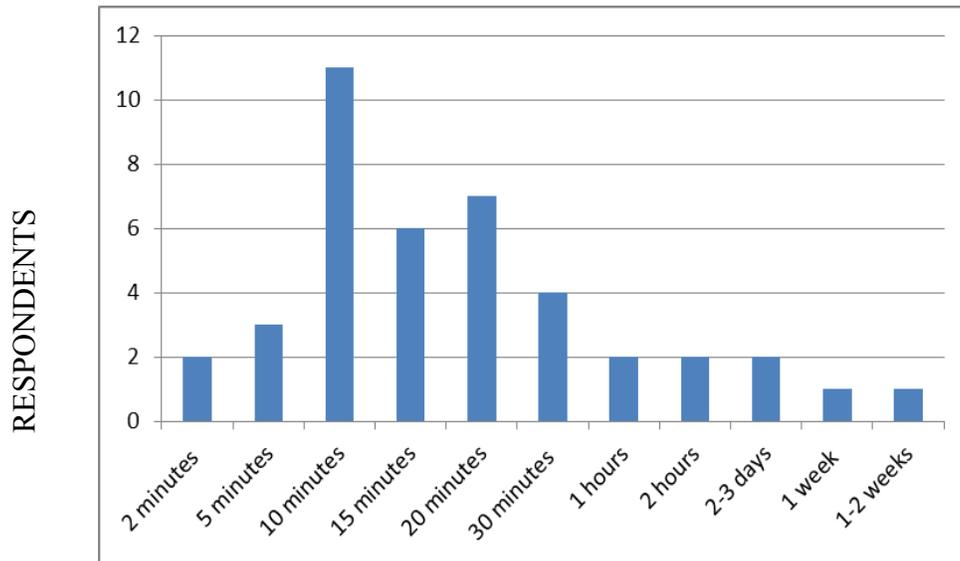
Other comments were:

- Parents would need to do it together.
- Not with the help of ladies able to answer my questions.
- Premiums pd per year. This I had to call my employer to get, or find a paystub and do the math. Not a pain, but not quick either. Premium per month would be easier because it is right on paycheck (if from work)
- No, but if I need exact info, it would take time to obtain.
- No- except if you need detailed medical expenses.
- All info on pay stub so could use those, finding all information for other medical expenses difficult for two kids.
- Somewhat
- Gathering tax forms and pay stubs would take the longest.
- Some information was difficult to find.
- It was because my husband takes care of finances.
- No-guessed at the information.
- Somewhat
- Rounding up the paperwork was to some degree time consuming. Once we had it, filling out the form took 15 minutes. Gathering all the information and doing the form was an hour or so.
- Mutuals, stocks, bonds-- hard to find info and gather
- Not if paystub was available
- Just didn't have it at my fingertips but I could find it if truly necessary.
- Would be an added stressor to find the info and would have to fill.

How long did it take you to fill out the form?

42 people answered this question, two people skipped it.

Most replied it took them 10 minutes, followed by 20 minutes.



MINUTES TO COMPLETE FINANCIAL INFORMATION FORM

One person wrote “I wasn't able to find information but would estimate it would take about 15 minutes after searching for the information”

Other comments were:

- ... but not very accurate- estimated
- 10 minutes if I had all the information ready and available
- Plus time to copy pay stubs if I had really done so
- 5 minutes because I left the things I didn't know blank
- If I had to fill out all of the information exactly, probably about an hour
- Including gathering the information required
- Depending on the length of the hunt
- ...but no paperwork required, if it were, likely over an hour to gather paperwork

Q8. What are three questions or concerns?

Twenty-five respondents (57%) answered this question, thirteen skipped it..

Comments were:

- I don't make enough money. Full time student.

- Is it the same price no matter how many visits a month?
- Feel lucky to have ESS and would pay.
- Concerned if she'd stick with services due to the cost.

- What exactly will the money be used for? Will it be used to hire physical therapist?
- I hope budgets are not cut for this very important program

- Would it delay services/eval?
- Would refusal to fill out forms prevent a family from receiving services?
- Would our cost share be re-evaluated if our income changes?
- I think many first time ESS users will not understand the benefit and therefore not pay.
- Many families may have to choose between groceries or necessary therapies for their child.

- If it were on a computer it would help. Online would allow for more room if needed. Could do a little bit at a time..
- source of income makes it easier

- If you have two kids in ESS, do you pay two monthly amounts?

- Even a small monthly charge will discourage many parents from seeking ESS for their children. It's easy to convince people to get an evaluation and services when they're free but paying tends to make parents think there is something wrong with their child.

- Address boxes on form should be bigger.
- Form should ask for membership number, not group #, as it is usually what people know.

- Most people are already skeptical about [ESS Provider] and don't understand how their child would benefit, don't want to admit their child is behind, etc. I already hear "let's give it a few more months" before writing the referral. Many children have parents/siblings etc. who had a delay....sometimes when it wasn't considered such a big deal (e.g. my husband who had severe speech delay in the 1970s) so the delay isn't seen as abnormal or something that needs to be treated.

- Would you have to pay any insurance copays plus the monthly payment?
- Would this prevent some people from getting services? My older child has Katie Beckett. He received ESS but at that time didn't have Katie Beckett, didn't have the diagnosis yet. Would someone with Katie Beckett pay?
- Gross income plus what money is left over at end of month expenses are vastly different. Cost share should look more at what is left over each month.
- What will my insurance cover?
- Still cost share after insurance?
- Will staffing be reduced?
- Will a wait list be instituted for families that can't afford to cost share?
- When will cost sharing begin, if it does?
- Seems like a lot of information needed. Could cost just be based on income only?
- Although on paper it may appear that we could easily be able to afford \$100+ a month for services, when you calculate in car payments, mortgages, utilities, taxes, groceries etc there is only \$300.00 or so total that is left. I think the form should include additional information regarding monthly finances.
- Will we be turned down if we can't pay copay?
- When will this take effect?
- Will my services increase?
- It makes a difference on how many services she would be getting if we would pay. Families can't afford- costs more than insurance co-pays--too expensive. Families with income wouldn't be able to afford.
- Would cost of living and bills be taken into account, such as student loans?
- Would medical expenses/ special diets be taken into account?
- I am concerned about the overall cost, of course, and whether it will continue to rise once it is started. I think the fee will be intimidating to some families with children that require your services.

- If you are charging the parents, are you also continuing to try and bill the insurance company as well? It seems that people might be charged through this program and then through the insurance company as well. Is there any way to avoid this?
- Should make it clear if expenses are for the entire family or just child being treated.
- How do you determine how to equalize monthly payments for children who need a lot of services vs. those who don't.
- Will there be limits on services given per amount paid?
- Are you going to take into account expenses?
- Have you considered those guardians/parents who would not seek services for their children if there is a cost involved?
- Have you also considered the impact on the children if parents did not engage in ESS due to the cost?
- [Because of lack of referral to ESS and delay] my daughter did not have access to ESS which was [a huge financial burden to our family]. People need to know about ESS. Concerned that extra steps in the application process, some kids will not have access to ESS. I feel that ESS should stay as it is. The services and therapists have, as a mom of 5 young children, provided the services my children need without causing the rest of the family to suffer.

Q9. Any additional comments?

Nine people answered this question.

- It is important child gets what he needs.
- I think this would be a great thing for the program and the families involved.
- They should be able to cut from other programs and not from important ones like early intervention.
- Good without copayments but not that high if you had a lot of services a month.
- Does it take into account expenses?
- If we were in that situation it would be difficult- understandable. If we had to we would, but it might be difficult.
- Maybe other income could be put on instead. It would be better to do income after.

- I like not paying, it makes it easier to get services for the twins.
- It's not fair for some people who can't afford it.
- I wouldn't have the time to do the paperwork.



The responses to the Family Cost Share Pilot Evaluation were:

Q1. Was the concept of a family cost share difficult to explain?

All 7 respondents replied no.

Comments were:

- We relied on the paperwork to explain it .
- This was an easy concept to explain
- I found this pretty simple to explain and families were very receptive to the idea. It's pretty straight forward
- Not at all.

Q2. Did you find you were missing information?

Two respondents replied yes, five stated no.

Comments were:

- Families didn't ask questions so it seems we had everything we needed.
- Families wanted to know why EI would receive budget cuts when it is such an important program.
- I was able to answer any questions with the info I had.
- How would assistance be provided if they couldn't pay copay.
- Packets were very comprehensive.

Q3. Were the families, in general, able to provide all the information required in the

Comments were:

- They provided a rough estimate. They were concerned about accuracy. It was difficult for those who were self-employed
- One family did not want to disclose income info, and another did not have the info easily accessible (they guessed on the form)
- They were able to estimate, in general, the information for the form, but many of the moms really had no idea what the monthly income/expenses were. Finding the information was difficult. Many of them let the husbands handle it.
- A few mothers needed to ask spouse for info but in general they did not feel it was difficult to provide.
- Yes but they said if they really had to provide paper documentation, it may have been difficult at initial referral.
- I explained the survey etc and then entertained their children in order to give them privacy. I had them put it directly in envelope in order to keep info confidential; therefore I am not certain paperwork was filled out fully or accurately. Families did not ask a lot of questions or seem to struggle with it.

Q4. What were families reaction to having to give personal financial information?

Comments were:

- No problem because it was without identifying information.
- See above. Plus one family mentioned that "other" expenses aren't included on the form (mortgage, car, utilities, etc)
- They were fine for the most part. One family would have liked to fill out the info with her husband and mail in separately. She called to change answers afterwards.
- In general families has positive reactions and stated they would do anything to get their child what they need.
- They were OK with providing information when they knew it- a lot was very estimated. One family was hesitant until assured it was anonymous.

- Since it was anonymous, they were less concerned but most were an "open book".
- Only 1 out of 5 seemed uncomfortable with it.

Q5. Was the process straightforward?

Six people responded yes, one skipped the question.

Q6. Any additional comments?

There were five responses to this question.

Comments were:

- Questionnaire would have been more informative if they had been phrased as open ended questions rather than yes/no. Many of the families had limited responses. They also wanted to know how they would receive financial help if they couldn't afford the copays and if they could get more frequent services b/c they were paying copay.
- Families asked if everyone would pay something, even if only \$5. One mother stated for those who don't meet the income level should pay something. Another one thought cost was too high and wondered if cost would also consider the amount of services per month. For example, child receiving 1x/month should not pay the same as a child receiving weekly services.
- Most families stated they would prefer 0 copays, but if they had to they would.
- Hardship could be more challenging- but it is a needed process. My main concern is the family cost share process would happen with families at the intake, before they would know and trust us. Follow through with this paperwork will be required and some parents won't do it, leaving the (potentially) most vulnerable kids without services.
- The conversations with most families were positive. Allowed me to connect in a QA sense as well. A couple of people would have paid that day.

