

Negotiating Contracts with FSCD and PDD

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Negotiating contracts with Family Supports for Children with Disabilities (FSCD) for our minor children or with Persons with Developmental Disabilities (PDD) for adult children who qualify, is fraught with anxiety for many families. Our child or adult child's well-being, and that of our family, is closely tied to the case we can build and the funding we can negotiate to ensure both child and family are safe, secure and healthy.

Roma Kurtz and David Jardine are both parents of high needs adult children with autism. Both have years of experience negotiating funding with FSCD and PDD. They were on hand at ASEA's Parent Information Night on November 24, 2009 to help take some of the mystery out of negotiating contracts. Below are some of the highlights of their talk.

Prepare Carefully for Your Contract Discussions

Negotiating your contract with your FSCD or PDD worker is not a casual conversation; it is a discussion concerning an agreement that can involve substantial sums of money over the contract period and that may be vital to your child and your family's well-being. For that reason, it is very important to take the time to prepare in detail for the discussions concerning a proposed agreement.

This type of preparation takes substantial time and effort but it is vital to help you prepare materials for your worker that describe your child's needs, your plan for your child, and the amount of financial support you need to make the plan work. The sections below will help you identify the information you need to gather.

1. Obtain as much information as possible about what FSCD and PDD can offer in a contract

In preparing to discuss a contract, it is important for you to have as much information as possible about what types and amounts of support are available and to know as much as possible about what other individuals and their families have received.

FSCD and PDD each have specific regulations and policies that set out their mandate, the individuals that they serve, and what services or supports they can pay for. You can get general information about these matters from the FSCD or PDD websites [insert references?]. Your worker can also provide you with general information about what supports may be available.

However, for more detailed information and for some understanding of what is actually being funded, one of the best sources is other families who have gone through the process and who continue to deal with FSCD or PDD.

Organizations such as ASEA or the Alberta Association for Community Living may have staff who can provide some of this information or who can connect a family new to the process with other families. This type of practical information and feedback is very useful in preparing to discuss a contract.

Such contacts may also help the family to know what supports are available in the community, what agencies provide those supports, and whether the existing agencies have openings for new clients. This is important because families will need to determine whether they wish to work with an agency or whether they wish to provide family managed supports where the family acts as the agency in finding staff, supervising staff and administering the funds provided by FSCD or PDD.

2. Build the Relationship!

Initial Contracts

Whether you are dealing with a first contract for your child with FSCD or your young adult's first contract with PDD after they turn 18 (assuming they have been accepted as qualifying for PDD), you need to know that you are establishing a long term relationship with the funding agency and that first impressions and first contracts are important.

In your first dealings with your FSCD or PDD worker, your job as a parent is to help your worker understand your child or adult child and his or her needs. Remember that your worker does not know your child and will begin with limited information. Help him or her to get as full a picture as possible, especially concerning your child's areas of need, and the challenges faced by the child and your family. Remember you are building a record of your child's needs that will be maintained on file and will be referred to in future years by FSCD or PDD staff.

Some matters to consider include the following:

If possible have your worker meet your child. If this cannot be arranged, provide photos so the child is more than a name. Let your worker see your child at various activities, or show photos of your child at various activities. Give them a picture of what the child's daily life is like and where they need to be supported and what challenges the family faces in providing support and safety for the child or young adult.

It's important to share your child's strengths and positive sides, but in today's world of funding cuts, the health and safety of children and adult children with developmental disabilities take priority. Be sure to emphasize to your worker your child or adult child's basic needs for health and safety. If your child cannot keep him or herself safe and healthy, your worker needs to know that. Let your worker know the amount of time, care, supervision, organizing and other supports that are needed to ensure your child's health and safety.

When you talk to your worker outline the areas where your child is not able to be as independent as others at the same age, and give examples so your worker understands your child's basic needs for health and safety. Prepare for the meeting by putting together an itemized list illustrating why your child/adult child will not be safe if left unsupervised and give examples. This will be different for children in different age ranges, but evaluate your child in the following areas and provide details and examples:

Can you leave your child alone at home or in public?

What might happen if your child is left alone at home or is not supervised closely? Will he or she become a danger to him or herself? Give examples where possible. Examples given by David and Roma included:

- turning on a burner and putting something flammable on it;
- leaving water running and overflowing sinks or tubs;
- leaving home and wandering in traffic;
- hurting him or herself or damaging property;
- tasting or ingesting harmful substances;
- unanticipated but potentially dangerous situations g like pouring water on electrical appliances such as computers or light bulbs;
- starting in small fire.

Can your child or adult child care for him or herself independently?

Again give examples where possible and consider questions such as the following:

In the Home

- Can your child dress him or herself without assistance or a prompt?
- Can he or she complete daily grooming activities independently?
- Is your child able to initiate feeding him or herself and make a meal?
- Can your child use a key? Will he or she remember to shut and or lock doors?
- Does your child put him or herself to bed? Does your child sleep regularly or does your child have an unusual or non-existent sleep schedule?
- Can your child use a telephone or get help if an emergency were to occur?

In the Community

- Can your child access the community independently?
- Can your child speak clearly enough to be understood by others?

Can your child cross a street safely/ can your child take public transportation independently?

Does your child know his or her address and how to get home?

Can your child wait in lineups in public areas?

Can your child behave appropriately in public or does he or she require assistance to take advantage of community activities? Consider how your child behaves in restaurants, in stores, at public events, etc.

Are there examples of activities outside the home that your child enjoys but needs support to access?

If you have prepared a list or written description, give the worker a copy so it can be placed in your child's record for reference in the future by new workers or other staff who are reviewing the file.

Recognize that your worker collects the information and makes recommendations. She or he is not the final decision-maker on contracts and the worker is required to follow certain policies or limitations. Do not attack the worker personally when problems arise. Be polite and professional in your dealings with your worker even when you disagree with what you are told. As much as possible, try to keep a positive relationship with your worker.

Remember that your relationship with FSCD or PDD will be a long term relationship and that you do not help your child by saying or writing things that may come across as angry or abusive to someone reading them in the file.

3. Have a clear idea of what you are asking for your child.

While most FSCD or PDD workers are professional and helpful in a general sense, a family cannot rely on the worker to identify what their child needs, what services are available and how much funding is required. This is something the family must develop for their own child and that child's specific situation and needs.

This can be a very difficult process, whether it is for a family whose child has just been diagnosed or a family whose child is transitioning from the FSCD program to the adult world of PDD. It also differs with a child's age and specific needs.

Where a family is working with an agency, some of this work may be done in conjunction with the agency but it is still important for the family to identify and understand their child or young adult's needs and the supports they require.

The following are some general areas that need to be considered:

- a. What are the Needs?

A good starting point is to consider what the child or young adult's daily or weekly life is like. What does a typical day or week look like for the child and the family from the time they get up until the time they go to bed? During that time are there particular points of the day or week where problems arise because there is no support?

Try to identify the kinds of support you and your child need:

Is it respite to provide breaks to the family members who provide daily support and supervision and who will burn out without some breaks?

Is it intensive programs for the child (for example, ABA/IBI programs) to assist their development over and above what is provided by the school?

Is it after-school care for working parents of school-age children for the period between school and when the parents get home from work?

Is it aides to assist the child or young adult in community activities?

Is it a day program for a young adult?

Is the child or young adult able to live at home or will residential support be needed?

Describe why the supports you have identified are necessary for the health and safety of your child and for their growth and development and inclusion in the community.

b. How Much Time/Support is Required?

In addition to identifying the types of support needed, it is important to have some sense of how much support is required on a daily or weekly basis. In general FSCD or PDD contracts provide a certain number of units of support which represent the time of an aide or support worker. These are usually set out on a monthly basis.

Try to develop a plan that breaks the time you need for support down on a weekly and monthly basis for each of the types of support you are asking for. This will give you a general sense of how many units of support you are asking for.

For example, with a school-age child, before you meet with your worker count the number of school days and the number of non-school days in your contract period (school boards generally have these online). Figure out how your needs differ on school days and on the days when there is no school. Does your child or adult child require additional supervision on non-school days? How many additional hours are needed on those days?

Count the hours you need for school/ days and for non-school/ days. Remember also to include respite hours for yourself and your family – on both weekly and annual bases. You cannot provide constant supervision to your child over the years without adequate rest or you become a health and safety risk yourself.

While a young adult who has transitioned to PDD at 18 may be able to continue to attend school until the year in which they turn 20, very different needs arise after that time. With school no longer available, a family must plan for additional supports for the young adult for the time previously spent in school. This is a major transition because the lack of school creates a large gap in each weekday that will require additional supports.

c. How much will what you are asking for cost?

For each contract, FSCD or PDD sets out a budget based on a certain number of units of time multiplied by the available rate they will pay for the type of support being provided. Find out from FSCD or PDD what rates and units they use to calculate budgets. Ask what hourly rate they pay for respite services, community access services, specialized services, etc.

With this information, try to develop your own draft budget that breaks down the type of services you are requesting into specific amounts of time. Then calculate the cost by taking this time and multiplying it by the rate for that type of service.

While this process can be time-consuming and may seem difficult, it is important to understand the costs of the services you are requesting. It shows the worker that you understand the basis on which contract budgets are determined.

More importantly it lets you translate between units of time and dollar figures to understand how proposed changes in the number of hours or the dollars offered can have major impacts. This will be important in responding to proposals from FSCD or PDD if they do not accept your original proposal.

For example, it is important to know that an offer of a contract with \$2000 of respite support for the year translates to approximately 120 hours of respite for the year or 10 hours per month or less than 2.5 hours per week based on an hourly rate of \$16.50. If you have determined that your family needs 30 hours of respite a month, you need to know that the cost for this would be more like \$6000.00 and to explain why 10 hours a month would be inadequate.

It is also important to know what the rate paid by FSCD or PDD covers. Generally, the rate includes the employer costs for staff for CPP and EI deductions and it may or may not include any payments due to WCB. This means that although the rate paid may be a certain figure, the actual figure you can pay your workers is less because you must also pay these other costs. For specialized services, the amount in your contract may be used to pay for transportation costs for the specialist, planning, report writing, and meetings that reduce the hours of direct service your child will receive.

4. What contributions does your family make?

Particularly in this time of budget constraints, both FSCD and PDD workers will ask this question and will want to show they have done their due diligence in ensuring the family

is making a contribution to the care of the child/adult child. This can feel like an uncomfortable or even insulting question but rather than getting angry it is better to be able to describe in detail the many contributions your family already makes to support their family member.

Before you meet with your worker, itemize the contributions your family already makes to your child's well-being. In doing this you may want to consider the following:

- a) While school or a day program may occupy your child's time for a portion of the day, most families provide supervision, safety and security for the remaining hours of the day. If your child is in school or with a caregiver for 8, 10 or 12 hours a day, you as the family provide the same service for the remaining 16 or 14 or 12 hours a day – a service FSCD or PDD would have to pay someone to do if you were not doing it.
- b) Many families provide a range of administrative services. They advertise, interview, screen, hire and fire the people who work with their children. These can be very time-consuming tasks, which families provide for free. Many families also provide payroll services including maintaining records of hours, calculating payroll deductions and/or units and how they have to be billed, as well as banking and accounting.
- c) Families are always on call to provide emergency relief any time a worker cannot make it to work – usually at the cost of the family's own employment and income. In some families, one parent does not work full time as he or she must be available to manage the child's life and the workers who help him or her.
- d) Families often provide many supports that are not funded by FSCD or PDD including shelter, food, clothing, recreation, and sometimes the professional services of therapists or other professionals.

Having a list of these contributions and the time and cost involved can usually satisfy this question.

5. The Right to Appeal

At present, both FSCD and PDD are under significant financial pressure. They are allotted a particular amount of funding by the government and are serving a growing client base with budgets that are not keeping pace with the funding needs.

This means there is significant pressure on FSCD and PDD to contain costs and this may be reflected in the response to your proposed contract. It is also one reason why families must be cautious in simply accepting whatever initial figure is offered by FSCD or PDD. A family is not obligated to accept an offered contract that is inadequate to meet the needs of their child.

Both the FSCD and PDD statutes and regulations give an individual or their representative the right to appeal a decision regarding funding to an appeal panel. If it appears that you are unable to resolve the contract issues with your worker and you are offered a contract that you feel is inadequate, you may need to consider filing an appeal.

There are several important points to consider in relation to an appeal:

- a. there is a specific time limit within which an appeal must be filed that can be quite short (as short as 30 days after you receive the decision) so make sure that you get advised in writing from your worker as to what the time limit is for an appeal and when the appeal period begins in your case;
- b. if it is suggested that you have further discussions with one of your workers supervisors or more senior staff, get confirmation in writing that your appeal period will not start or continue while these discussions are taking place;
- c. there are specific appeal procedures and guidelines that are available to persons who are appealing a decision. Get this information as soon as possible from your worker or the FSCD or PDD office. General information on appeals is also available on the websites;
- d. find out the basis on which your contract was rejected or reduced and try to get this in writing. If you cannot get something in writing, send a letter or email confirming the information you were given verbally;
- e. make sure you file the appeal well within the time limit and that you get confirmation that your appeal was received;
- f. review the appeal procedures to make certain you understand what will happen at the appeal and what documents and information you need to provide;
- g. you are entitled to see the information on the FSCD or PDD file and the recommendations and reasons why your requests were not approved – ask for this information as soon as possible so you can use it in preparing for the appeal.

Even after you have filed an appeal it is worthwhile continuing discussions with more senior staff at FSCD or PDD. Sometimes these discussions will result in changes that give the family most, if not all, of what they need without the need for a formal appeal hearing.

If you are proceeding with an appeal, consider contacting ASEA or the Alberta Association for Community Living to see if they can provide advice or help or put you in contact with other parents who have gone through appeals who may be able to provide advice.