

REGIONAL SUMMARY REPORTS

for the Persons With Developmental Disabilities
Community Conversation Report

from Genia Leskiw, MLA for Bonnyville-Cold Lake to the Minister of Seniors and Community Supports



Regional Summary Reports

Reports contained in this section are designed to provide a reflection of the reoccurring themes within each of the sessions. They were created by reviewing the notes collected over the course of these twelve focus groups and a great many written submissions. Each region has a dedicated appendix containing:

- a. The Moderator's summary speech, as delivered, from each session
- b. A summary of key themes from the family member and service provider session
- c. A summary of key themes arising from the self-advocate session

These summaries are not intended to report all the specific concerns from each participant in the focus sessions. Rather, these summaries reflect the general feelings and concerns of those who attended, using participants' own language as much as possible.

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St. Paul

St. Paul – June 7th

Moderator's Summary as Delivered at the Session

Well, what a good morning of discussion and learning. We really appreciate the time you've spent with us, and your generous contribution of ideas.

We began this morning with a clear commitment from MLA Leskiw to listening, getting your input and using your advice to improve the PDD system. This project's MLA leader also made it clear that nothing, I repeat, nothing, is going to happen quickly or reactively. This process of contracting reform will be methodical, careful and tested before any changes are made.

Then Dale Drummond gave you an overview of the changes recommended by KPMG, and set the context for your conversation about the contracting process. He gave you an update on PDD action in the region, and reminded us that what PDD is aiming for is a consistent and rigorous contracting process across the province, one that makes sense wherever you may live in Alberta. Great services, improved contracting, and most importantly, better outcomes for individuals.

Then it was your turn, and the room really got lively. Your input was great. When you started to talk about being outcomes-based, you talked about goal setting and shaping a meaningful life for your loved ones, and I heard you say that not all service provider and family relationships are working effectively. Parents said that they're not always clear about what goals are being set for their family member.

You helped each other understand the importance of being clear about what you want for your family member – and feeling safe to ask for it – and require it. An expectation of high quality service is perfectly reasonable, I heard.

Service providers talked about the fact that PDD contracted service limitations can sometimes inhibit creative service provision, and what's critical is that families are involved in defining what is needed by being strong advocates. Getting the balance right between service provider expertise and knowledge and family wishes, you said, is absolutely critical. And this balance is trust-based and relationship-based, and builds over time.

You talked about the importance of planning together, and setting ambitious enough goals for individuals. I heard you say, repeatedly, that being agile, being able to shift and adapt is really key. Goal setting is not a fixed activity. It's ongoing, it's continuous, and it has to be ambitious. Contracts, as well, have to be as flexible and evolving as the goal setting process. Family members told us that service provider and agency expertise can sometimes not take individual insight into account. You know your loved ones best, and your family expertise needs to be respected.

True inclusion, you said, is being able to make decisions about your own life, and having control over your future. You reminded us that this is a fundamental need for individuals, and any contracting process has to reflect this autonomy as much as possible.

You raised the complicated issue of individuals who are over-served, and the reluctance to give up service that a family may have fought for. This results in the status quo persisting, when, in fact, less service could result in positive outcomes. Clinging to service is a mindset that you all understand, even if it's not always best. There's a fear of service reduction that sometimes limits imagining new futures. And we *are* in the business of designing futures, you said.

When you talked about effective contracting, you asked questions like: *what kind of parameters should be in place for contracts* – so that they work well.

You said the contracting process needs to be open, transparent and accessible to all.

You said it's really important that competitive contracting doesn't turn individuals into a "commodity" and that the individual is thought of as a contract, rather than a person. Let's not forget, you said, that whatever business amendments are made, the bottom line here is that we are in the people business, and that is sensitive work.

You expressed concern that competitive bidding would in fact result in less choice of service providers to families. Competitive bidding must focus on providers who have track records of achieving outcomes, and not solely on the bottom line. And families, you said, should still have choice and support from PDD to select the service provider that's best for their family member. The grapevine works, you said, but it shouldn't be the only source of wisdom.

Families need to be supported in their decision-making and contractual relationships.

Even with family managed contracts, you said that the service providers who are hired work in a collaborative way with the families. There's shared wisdom that should be tapped into. You said we should be all in this together.

You talked about length of contracts, and some of you said that two-year contracts with ongoing monitoring make the most sense. Budgeting on a two-year cycle, you said, is more logical. And you made the important point that families should not be penalized if they didn't spend all of their annual money. Being efficient should not result in dollars being withdrawn. Two-year contracts with certainty about dollars would assist with this, you said.

You said, that PDD should communicate more broadly about its emergency fund so that family members can be assured that if their circumstances change, PDD will be there to support them.

You point out that family managed care can be exceptionally successful, but it's really important to think about networks, because when family members age and are no longer able to provide the leadership for the services, planning ahead and having a strong relationship with the PDD network is key.

You described the historic practice of parents "deferring" to agencies expertise, and that some of this behaviour persists. You talked about the importance of mutual respect and collaboration being extremely important. The issue of our aging population came up repeatedly. This is a demographic reality that we'll have to be very thoughtful about in planning for the future.

You also described the current situations where young adults are entering the PDD system at 18 with no family connection. Children in care who have transitioned into the adult system without a family connection. This, you said, is a reality that PDD of the future will have to face. The word “planning” kept coming up over and over again. And mutual planning that’s very high quality and completely collaborative has to be at the root of the contracting process, you said.

You raised concerns about the “one service provider” approach, particularly in rural Alberta where choice is already a challenge. You made the point, again, that choice for families should be more important than centralized single source service provision. You understand about efficiency, but you believe choice is more important.

You said you’d like staff accreditation to be reported and communicated, as well as licensing of homes. You talked about the challenges of measuring happiness, and you said you want client surveys to be transparent. You said that how indications are used is important. Because these, like statistics, can be used to distort reality. For you, trust is central to effective performance measurements and communication of performance. There has to be, of course, a close alignment between outcomes and performance measurement. Put simply, the goals should drive the plan and the achievement of goals should drive performance measurement. This loop has to be clear, logical and not overly complicated. You described “Scope Builder,” which you said didn’t really fit the bill of uncomplicated.

Measuring outcomes, you said, is much more important than reporting on activity. While you recognize that it’s difficult to measure outcomes, every effort should be made to find and use meaningful tools to capture this information. You also made the point that the individuals own perspective on their happiness should be solicited. Who better to comment on our outcome than the individual themselves, you said!

You talked about positive changes for the future, and you said there should be better planning for respite and more prominence for the role of the PDD client service coordinator. You said that performance based organizations have to be transparent, consistent across the province, and values based – and stay true to those values. Have a customer service philosophy, which means answering the phone, being available – being truly service oriented and helpful. Performance based organizations, you said, must first of all, perform.

Thank you St. Paul for your great input.

St. Paul – June 7th

Morning Session: Family members and service providers

Summary of Key Themes Explored at Facilitation

BEING OUTCOMES-BASED

How can service providers and contracts enable an outcome-based focus?

Participants said:

- Families need to be involved in the process of making and monitoring contracts
 - No one knows my child like I do, I'm a valuable resource in defining outcomes and identifying results
- Service providers need to be heard too – it has to be a collaborative, trust-based relationship
- We need to evaluate the goals frequently – readjust, realign, retrack
 - Contracts need to be flexible enough to support this evaluation
- Consider the importance of individuals having a say in their own care

What's getting in the way of being outcomes-based?

Participants said:

- Conflicts between service provider and family are a barrier
 - There is an important need to foster relationships between the two
- Administration like service units and year-to-year contracts dominate the system
 - All the time put toward administration is time not put toward individual outcomes – but that's our mission
 - We can't deliver on outcomes when we're just counting hours
- Funding has not kept up with support requirements and outcome expectations – we're being asked to do more with less
- System can be confusing for parents and even service providers
 - What is the role of PDD vs. the service provider?
 - Who should families be dealing with?
 - What is the relationship between service providers and the PDD office – define who they are beholden to?
- Staff turnover impacts the outcomes of individuals
 - Trained staff leave the sector because their pay doesn't reflect their value
 - If you value people and value resources, you will have valuable outcomes
- Families who may be over-served in term of needs are reluctant to say anything fearing that they'll lose too much service

- Issue of trust and understanding in the system

NEW CONTRACTING PROCESSES

What are the most important aspects of a contracting process?

Participants said:

- Contracts should be built to create and foster relationships
 - Families and service providers need to work together
- Contracts need to be open for everyone to provide input
- Transparent – documents should be available early
- Standardization of service coordination and PDD-issued material across regions
- Succession planning for aging family members and guardians needs to be addressed – we need to plan for the possibility of clients with no family connection
 - This is a problem already evident with some youth entering into the system

What are things to avoid in a new contracting process?

Participants said:

- Don't lose individuals in this process – keep the focus on them
- Families need to have as many choices as possible – make sure they can help meet their own goal
- Relationships in rural areas are important to delivering care – changing service providers can sever those
 - Small rural service providers are invested in their community and have better access to community resources and crisis supports
- Financial uncertainty
 - Tie money to the individual, not the agency
 - Allow money to carry through from year to year
 - Don't penalize efficient service providers by clawing back dollars on a year-by-year basis

What are the advantages/disadvantages of competitive bidding?

Participants said:

- Advantages:
 - Funders could know the agency track record and make it available for families
 - Ability to involve families in determining outcomes and outcome measurements
 - Some potential for shared services
- Disadvantages:
 - Worry about “commodifying” individual care

- We can't apply business practices to human care
- Taking the lowest bid is a concern
 - Awarding bids has to be for the best service, not the best price
 - Worry that bidding will devolve to the lowest bid, regardless of our initial intention
- Bidding may reduce choice of service providers
 - We can't meet individual needs if we don't have choices
- Competitive bidding may prevent family managed care from participating
- Potential for creating detrimental changes to clients – clients thrive on consistency

What do you think about co-operation among service providers?

Participants said:

- Lots of service providers are already doing this
 - Sharing training/administrative support
 - In rural areas co-operation is necessary
- Mechanisms for contract review
- Training for Family Managed Services are important for the overall quality of the sector
 - Family managed services might broadly benefit from accessing agency services

MEASURING PERFORMANCE

What should be measured?

Participants said:

- Measuring outcomes for individuals is the most important measure
 - Client and family satisfaction are an important outcome to measure
 - Client input is particularly important
 - How relationships with families have evolved since the start of contracts
- These are not easy aspects of care to measure, but we need to go beyond just measuring activity – we need to look at results

What should be reported?

Participants said:

- Level and consistency of communication with families
- Staff turnover rates
- Expertise available within the region
- Issues as identified by CET

What needs to change about the system in order to become more performance-based?

Participants said:

- Respite planning needs to be planned better, further in advance
- Use what the individual and the support network say about how the individual feels about their care as the measurement model
- Transparency and consistency between regions
- Service providers need to adopt a more customer-service oriented approach
 - Regular, reliable response timelines
 - Specific client service coordinators should be available
 - Crisis response needs to be quick

St. Paul – June 7th

Afternoon session: Self-Advocates

Summary of Key Themes Explored at Facilitation

What makes life better?

Participants said:

- “Right supports, right time”
- Assistance/advice services would be helpful for an independent person
- Grocery/transportation support could also check apartment and give feedback every two weeks
- Panic buttons so I can reach out to people when I need them to make my life better
- Support group makes my life better
- Being active, having work, work with flowers in garden
- Going places with friends
- Being short of money is difficult
- Having a family member who doesn’t listen or understand is difficult
- Working hard gets you ahead
- Helping people makes my life better – working

What has to change?

Participants said:

- Someone to listen
- One-on-one staff to help once in a while
- Reliable work where I’m kept on
- Someone to look out for me
- Help with cooking
- It would help if it was easier to make friends and connections
- Healthy meals/cooking: Meals on Wheels, help with supper
- Help organizing shopping for clothes and other necessities
- Activities besides bowling
- Place to “hang out” and be comfortable
- Language is too vague
- Too complicated to talk about contracts
- In rural areas – only single service providers and family managed contracts

- Home care services for AISH. E.g. cleaning appointments, someone reliable
- Medical services at home is good

Is choice important?

Participants said:

- Choice tough when short staffed
- The work for PDD is hard work, there is high turnover – change is hard

Can you tell service providers what you like/don't like?

Participants said:

- Yes, but it doesn't make a difference – they are short of people, scheduling is tough
- They help with medical appointments, but that time is taken away from other services
- They say “If you don't change, you're never going to get anywhere”
- Service provider should ask about needs “how can we help you
- Can tell service provider what I want/need
- Need help after hours

One thing you wish for to make things better

Participants said:

- Would like evening/weekend medical support
- More money
- My mother back
- I like the way things are
- A good experience would be typical for all
- Protect people at night



Red Deer

Red Deer – June 8th

Moderator's Summary as Delivered at the Session

What a great morning of discussion, when you talked about outcomes, you gave us lots of input. For example, you said that you want much more visible and intimate relationships with the actual front line people who support your family members. Families told us that sometimes they don't even know the person who's offering the service to their family member and this lack of relationship is a real challenge.

You said that while moving towards technology improvements are great, the reality is that the current system remains very paper-driven, and paper work detracts from service provision.

Concerned family members expressed that they want to be handled with care – like humans with needs, and that for them, policy and procedures are less important than people. This is ultimately a people-business and the operative word is people.

I heard that service providers are deeply committed to best practice, but that actual best practice isn't always evident.

“Relationship” is a word that came up over and over again, because all of this work revolves around relationships.

You talked about the tension between the service provider expert and the family who knows their family best. You said that shared expertise is the best way to go.

You talked about the mysteries of language and jargon, and how it becomes necessary to learn a whole new PDD language. What happened to plain language and common sense, you asked?

You talked about the importance of consistency and a constant presence. Someone who can become your guide on the PDD journey, and in particular, someone who can aid in the transition from 17 to 18, from the Children and Youth Services System to PDD. It is a difficult enough journey, you said, without you having to navigate two systems, both of which can be complicated.

Given where we are, it's natural that we would have talked about the Michener Centre, and the value it adds for many families. This was an important perspective to be heard.

You said that you don't know enough about the staff who are working with your loved ones and you made the point that given the wage level, the sector doesn't always attract the most consistent people. This proves to be a challenge for families who are looking for constant, healthy, long term relationships.

When you transitioned to talking about contracting, and how to make it better, you said that collaboration on contract development is important. PDD/service providers/families should work together cooperatively. Right now, you said, contract development tends to be one-way and somewhat top-down.

For a people business, you said, there has to be a better way of building contracts and ultimately, building relationships.

You described that the paperwork and administrative processes that the Alberta Government requires can be quite overwhelming, and so co-operation between ministries is very important to you. Could the Government of Alberta, you asked, operate as one government delivering seamless service that transitions individuals naturally through the system? It's straightforward customer service, you said, being truly committed to making the service as easy and user-friendly as possible. You shouldn't have to learn the systems – the systems should work for you.

You talked about the importance of transparency. Your service providers should share information about services and costs in order to increase accountability, and should be very clear about what's being provided. Again, back to the issue of "we're all in this together", surely the system can be as transparent as possible. That's the essence of professionalism, you said.

You talked about competition between agencies and how this represents a challenge for you. What you're looking for is agencies that operate openly, are focused on individuals lives, and are extremely service oriented and respectful of their clients and their clients' families.

You talked about family managed services and how they should be on par with the level of service received from agencies.

When you explored shared services, you raised the issue of how that might require a standardization of services. This, for you, represented a risk of "pigeon holing" and "one size fits all". This is a challenge that just doesn't work when you're talking about people. You also expressed concern about accountability when services are shared. How would that span of control be handled, you asked?

Many, many times the issue of the caliber and quality of service provided came up. This sector deserves well-qualified people with excellent judgment because they do very sensitive and important work, and continuity is key. It comes down to trust, you said.

When you explored the idea of unified agencies, you said that at its best it does represent more choice from one entity, but if there's any relationship breakdown with that service provider, then choice is completely lost, and that this poses some risk.

When you drilled down into some specifics of competitive bidding, you said that working this out has to be done very carefully, because you don't want business principles to trump common sense and good care. You're not closed to competitive bidding – you just expressed caution.

When you talked about performance measurement, you said highfalutin measureable outcomes may have their place, but how do you measure smiles, how do you assess a contented family member?

What you did say about measurement is that it has to measure the positive and the negative. Any kind of performance system has to be subtle and simple enough to capture what really matters, and what demonstrates satisfaction.

You said that there has to be a safe culture for effective evaluation, and families should feel absolutely safe to express their views. Currently, that's not always the case: families tend to try to "fly under the radar" so that they don't rock the boat. In a healthy culture, you said, performance measurement is expected and honest feedback is welcomed.

The issue of community-based salaries versus unionized staff salaries was brought up. What you identified as a wage inequity causes challenges, you said, because community agencies need to be able to attract people and pay them accordingly. Staff issues, you said, are huge. Creative programs need to be in place to keep staff healthy, happy and appropriately compensated. And you said that current privacy laws prevent you from being able to drill down into your worker's employment history but hiring practices have to acknowledge what the needs are of your vulnerable loved ones.

You talked about the fact that there is a lot of good going on in the PDD system – it's certainly improved over the years, but it has become more administratively heavy. Contracts can be improved so that they support the service delivery system better, but any contracting reform, you said, needs to be sensible, not paper-heavy, service oriented and evaluation focused. This is really about getting results for individuals, not just providing service.

You made it clear that quality of service begins with good planning, mutual respect and trust as well as a commitment to sharing information about results achieved. Quality of life for individuals is ultimately what is most important ... that's what must be measured and planned for.

Thank you, Red Deer for your helpful advice.

Red Deer – June 8th

Morning Session: Family members and service providers

Summary of Key Themes Explored at Facilitation

BEING OUTCOMES-BASED

How can service providers and contracts enable an outcomes-based focus?

Participants said:

- Contracts should be about needs and how to meet them
 - All programming should be individualized as much as possible
 - Knowing the individual is key to determining appropriate outcomes
- Guardians need to be encouraged by contracts to be involved in care and establish personal relationships with service providers
 - Guardians and family members are the experts on their loved ones – it's important that expertise gets shared
- Protect service relationships by retaining staff – this is the key to providing consistent supports
 - Wage increases for providers (possibly from administrative savings)
 - Provide training for providers to deliver consistency
- Start involving families in creating ISA's
 - ISA's contain flexibility to change as needs evolve
- Contracts need to be flexible to meet evolving needs
 - Flexibility can't come at the expense of care – it has to be a condition use to enhance individual care
- There needs to be some consensus on what “outcomes” and other terms mean to everyone in the system
- There will need to be succession planning as guardians and family members age

What's getting in the way of being outcomes-based?

Participants said:

- Agencies are often held back by administration
 - Long lead times to have expenses and contract changes approved
 - Can't afford to provide services they want to or are asked to
 - Have difficulty problem-solving issues basic to individual care
- Spending time on administrative duties pulls time away from providing supports
- Transitioning from CYS to PDD can be difficult

- Before my child turns 18, they should know more about them
 - Frustrating to have to tell your stories over and over
- Contract restrictions limit service choices because they won't pay for expenses like mileage
- Untrained, constantly changing staff are hugely disruptive to care
 - Staff need to be retained
 - Before staff can deliver care, they need to meet core competencies
 - It is unfair to ask untrained staff to deal with highly complex care needs

NEW CONTRACTING PROCESSES

What are the most important aspects of a contracting process?

Participants said:

- Clear expectation that an outcomes-based model be used
 - Too much time is spent on accounting for photocopying, etc
- Clear understanding of what the available services will be from PDD
- Families and guardians need to be part of a collaborative contract development
- Funding for family managed services should be on par with agency funding
- Competitive bidding should be used if it can encourage better outcomes, not to save money
 - Tendering human beings is a tricky process

What are things to avoid in a new contracting process?

Participants said:

- Moving away from the principle of individualization if we move under an umbrella agency – will they be able to address unique needs adequately
- Losing the autonomy for individuals and families to make choices about where their care takes place and who it takes place with
- Making changes to contracts and providers too often will hurt the quality of supports

What are the advantages/disadvantages of competitive bidding?

Participants said:

- Advantages:
 - Could lessen admin expenses to PDD
 - Competitive environment could make agencies more accountable
- Disadvantages:
 - Staff job security may be threatened

- Loss of flexibility in services
- Loss of choice of services
- There will be no desire to bid for complex cases
 - Services for these cases may disappear
- Concern that the lowest bidder may always be chosen and that will affect system quality
- Agencies shouldn't be competing with one another

What do you think about co-operation among service providers?

Participants said:

- Great idea, potential to meet needs and save costs
- Some aspects of care, ie transportation, operate at a loss – perfect opportunity to cooperate between agencies
- Cooperating on training could be a stop-gap measure to the costs that result from high turnover

MEASURING PERFORMANCE

What should be measured?

Participants said:

- Individual satisfaction needs to be the key measurement
- Acknowledgement that measuring intangibles like satisfaction and happiness is difficult, but can be addressed with some clarity
 - Are they comfortable, healthy, has recent change been positive?
- Agency's level of collaboration
 - With other agencies
 - With family members and guardians on outcomes and care planning

What should be reported?

Participants said:

- Whatever is reported needs to look beyond the negative – it's important to know what is going well, not just what needs improvement
- Staff retention rates
- Quantity of contact with families
 - Honest, two-way communication is an important part of a healthy culture for all stakeholders
- Agency status under CET
- Ratings of agency-specific results

What needs to change about the system in order to become more performance-based?

Participants said:

- Focus needs to be on the quality of service, not the quantity of service
 - We need to do more than provide service – we need to achieve results
- We need to get over the fear that too much discussion and input on achieving results for individuals is going to lose money
- Supports need to consider that needs change day-to-day and throughout the life of the individual – flexibility in contracts will allow service providers to react to these changes.

Red Deer – June 8th
Afternoon Session: Self Advocates
Summary of Key Themes Explored at Facilitation

What helps you to have a good life?

Participants said:

- Equality
- Family
- Independence
- Volunteering in community
- Having friends
- Having a job
- Staff helping
- Having a home
- Being able to drive
- Parks/ trails/ access/ exercise
- Community involvement

What does not help you have a good life?

Participants said:

- Limited opportunities in community for groups to participate, e.g., Special Olympics.
- Not enough money
- No staff
- Limited choice of employment
- Labeling
- Health/ mental illness
- Abuse
- Prejudice
- Racism
- Insecurities/ bullying
- Relationships – not having them or having bad ones
- Lack of accessibility
- Crisis management
- Dealing with grieving

Do you feel comfortable talking to your service provider about your supports and how well they are doing?

Participants said:

- Yes. I trust them.
- Staff should listen and respond
- Really listening – someone who “gets you”
- Want to speak your mind about what is important
- Not listening when I object
- Can talk to family
- I can talk to a counselor
- Appointments are rushed, as if I don’t matter. Due to staff shortages.
- I get help with forms
- Bridge the gap – help others understand me.
- Sometimes they don’t follow service agreement

What is one thing you wish you could receive from your service provider?

Participants said:

- Help whenever I need it
- The winning ticket!
- More staff and more time with staff
- More communication/ better quality communication
- Do my own shopping – buy my own stuff – “What I want”
- Meet new/more people – make friends
- More patience when I have something to say
- Better treatment and mutual respect
- Flexibility of transportation



Lethbridge

Lethbridge – June 14th

Moderator's Summary as Delivered at the Session

What a rich morning of discussion and insight. Thank you for being so generous with your input.

MLA Leskiw set the tone with her commitment to listening, and Leigh gave us a helpful overview to ensure that you had a shared understanding of the administrative review and the contracting process.

Your opportunity to contribute to the outcomes discussion yielded some great advice. I heard some of you say that there is already a strong commitment by service providers to being outcome based – and this conversation should be about being better at being outcomes based and better at communicating those outcomes.

You reminded us that part of a service providers accreditation is about being outcomes focused and so perhaps what's needed is better alignment between accreditation criteria, PDD criteria and service provider criteria.

You said that listening to the individuals receiving service is key. Those of you who work directly with clients but may not be the guardian believe that your insight into the individual's needs should be respected and heard. This is, after all, a relationship-based business, and your expertise has real value. Better communication, you said, is key to making the relationships work.

You made the point, as families, that you have no direct involvement in the contract that exists between PDD and the service provider, and so this makes it difficult for you to impact contracts. But you do know what successful service provision looks like, and that's an important area for you to influence.

You raised a number of issues that impede great service provision, and one was – consistency of staff. For you to feel comfortable in the relationship with staff, you'd like to see professionalism, permanence, commitment and a sense of family. Because, for many individuals, staff become family; bonds are formed and staff disruptions are not only challenging, they can be heartbreaking.

You talked about the fact that PDD language and processes can be confusing. If they're confusing for families, how tough must they be for individuals? You asked for clarity, plain language and simpler processes. As family members, you live with a lot of uncertainty, fear of the future and insecurity about services for your loved ones – and you said PDD should try to allay those insecurities.

Centralization of services was raised as a real concern, you said it won't work, it's not in the best interest of individuals – and it's a worry for you that "efficiency" might result in amalgamation that could be negative for you. Bigger, you said, does not necessarily mean better.

Micro managing contracts, you said, is something you don't want to do – however, working in an outcomes-based way is important to you, because results for individuals are key for you!

You said, perhaps contracts should be called “agreements” in order to convey that sense of that mutual commitment. But whatever you call it, you said, the key is being flexible enough to truly accommodate individual’s needs and be results-oriented.

You described current PDD contracting processes as burdensome and paper-heavy and that dollars should really be focused where they make the most difference, with individuals at the front line.

When you transitioned to talking about contracting specifics, I heard you say that you were concerned that, in fact, new processes have already been determined and that these conversations may just be public relations. Your concern is noted, but the future contracting processes will be shaped by your input and everything you’ve shared with us has real value as the future is defined.

I also heard you say that contracts really do have to be flexible. Ultimately, you said, success comes down to the quality of the staff person. Delivering service, training, ongoing professional development, being able to attract and retain qualified staff are key factors for you. Everything you focused on is about better lives for individuals, and you said that right now the administrative burdens are an obstacle to being flexible, creative about service provisions. Contracts, you said, are too rigid, not relationship-based enough.

When you looked at competitive bidding, you said, that if PDD drives the decision about service providers, what’s at risk is choice for families.

You said that competitive bidding and collaboration among agencies is an oxymoron. These ideas are at odds with one another. Further, you said, that reducing service provisions to an RFP process is de-humanizing. You don’t want your loved ones to be considered as an RFP component. Let’s not lose sight of the people while we refine the process, you said.

At the same time, you applaud the accountability that is built into competitive bidding – you said, let’s be clear here that this is a human business and choice is key. We cannot, you said, “commodify” human services. Centralized decision-making, you said, would be a real problem – this was another significant caution that you expressed.

And how frequently does the RFP process run, you asked? Annually, for example, is enormously burdensome, you believe.

And you’re concerned that the dollar factor will be a deciding factor in awarding contracts, and again, another caution, cheaper should not be a driver of service provision.

You expressed concern that the search for efficiencies might actually end up being inefficient. So you said, to government, keep any redesign focused on the real bottom line – the lives of the people the PDD program serves.

Be practical, move slowly, look after the people first, not the process.

You did describe some benefits to RFP processes – you like what it could represent in terms of specifically about outcomes, and the rigour that service providers would have to engage in as they wrote proposals. Regardless, an RFP process has to first be outcomes-based because only when you know what you want to achieve can you cost out your service appropriately.

Our aboriginal participants were here to explore a range of ideas in order to determine what their future relationships to PDD might look like. We are extremely glad that you took the time to come and learn about PDD, and provide insight into what your unique needs are. You were clear that you want to shape a positive future for individuals with disabilities in your community. As a group, these individuals often face double discrimination – cultural discrimination and from a disability perspective. Your hope is that you can influence a better system for the future. Thank you for being with us to contribute your important perspective.

Your input on collaborative contracting was that at best it could be very cost-effective, particularly when it comes to transportation issues. For those service providers who deliver a unique service, you said that you have a concern about service providers becoming more generic and losing their unique identities and specializations. You also said that there are already some shared services happening among agencies.

For general training, first aid, abuse protocols etc, service providers do look for efficiencies in training already, you said.

Collaboration, we heard, begins with good planning and early determination of needs that can be jointly met. You said that you don't have much difficulty with multiple contracts, but to work well, they have to form part of an early and thoughtful plan. You also expressed concern that competitive bidding could make staff even more insecure "*will I have a job next year?*"

Clarity was another word that came up repeatedly ... and while you might be open to further collaboration, it has to be based on clear expectations, and most importantly, it must reflect the individuals' circumstances. You said that in the human services businesses, there will always be exceptions to the rule, and the system has to be able to be nimble and common-sensical enough to adapt.

When you talked about performance, you said that professionalism is key here. You said, front line workers should be responsible for developing their own individual plans, so that they work closely with individuals to define their accountability. It starts, you said, with front line accountability, and then agency transparency.

Accreditation results, you said, should be available publicly, as should the accreditation questions. You said PDD should play a role in gathering that data and sharing it.

Performance reviews, you said, should be frequent because they are the best way to determine success.

You said that performance measurement is in fact, an ongoing process and should be continuous, should be conversation-based, and not administrative or paper-heavy. Performance measurement, you said, is not a point in time, it's a commitment to ongoing continuous improvement.

Staffing changes should be very transparent at the agency level, because the issue of transient care is a real concern for you. You're looking for stability, continuity, and regular service. And you're concerned if agencies get too large or impersonal that these factors could be lost.

Parent conflict with an agency came up. You want to be sure that the protocol for airing a grievance is clear and that parents don't feel that it's detrimental to raise a concern. And you raised the practical issue of the risks of complaining and then not having services at all. Sometimes you put up with substandard care for fear of losing it entirely, you said.

The word "communication" came up over and over again. It works well, or not, depending on the skill of the front line worker. You couldn't stress enough how important this front line contact is, and PDD should not get in the way of that critical front line communication. You want service that is personalized, focused on the individual, accountable, realistic and professional.

You made the point that the concept of performance-based isn't necessarily clear. Who are we talking about here PDD? Service providers? Individuals served? If this is a web of relationships, in partnership with one another, then all players have to be equally committed to being performance-based. You said, a piece of this partnership is PDD – the funds – being very clear about what service providers do. Again clarity, and communication and a belief that we are all in this together as partners in building the best possible lives for individuals.

Your bottom line in this conversation was that people must come first – and that any changes in the future must be based on the human endeavour of meeting individual's needs. You said, the PDD system has to trust all members of the system, and move from monitoring to true accountability. Micro-managing isn't typically focused on results, and you said it's results that ultimately matter.

Your input was great – thoughtful, wise and extremely practical. Any changes for the future will be positively influenced by what you shared today.

Thank you Lethbridge.

Lethbridge – June 14th

Morning Session: Family members and service providers

Summary of Key Themes Explored at Facilitation

BEING OUTCOMES-BASED

How can service providers and contracts enable an outcomes-based focus?

Participants said:

- Focus on listening to the voice of the individual in determining their own care
 - Don't just assume that individuals are happy with whatever care they are given
- Families need to be able to give input and feedback into building individual plans
- Develop contracts that reflect that some outcomes are very long-term
- Outcomes need to be flexible so they can change and develop to reflect individual needs
- Stable staffing and the ability to develop a relationship with staff over a long period is very important
 - Relationship-building is key to good outcomes
- Match PDD contracts to CET standards – they are already outcomes-based
- Contracts need to be less admin-heavy
- Accountability measures for agencies need to be built into contracts

What's getting in the way of being outcomes-based?

Participants said:

- Time spent on administrative tasks impacts time that could be used to ensure a focus on individual outcomes
 - Management is unable to appropriately monitor staff outcomes reports
 - Mandated administrative functions like preparing binders take up too much time
 - Accountability measures are labour intensive
- There needs to be flexibility so that goals can change when the needs change
 - Consider calling them "agreements" to break the legality and formality of contracts and add flexibility
 - Can't currently engage in a long-term, 5-to-10 year contract
- Agencies are being micromanaged – trust that they will do the work
- There is choice restriction for parents
 - Cannot pay a family member to take care of an individual
- The system needs qualified and supported people working within it
 - Wages, especially for non-PDD service providers, need to be higher

- The system needs to be providing training, education and supports to staff
- Staff and service provider turnover is a huge barrier to improving outcomes
- Staff need to be consistent for individuals to succeed
- When services move, knowledge gets lost in the process
- The more vulnerable people are, the more changes will affect them
- Determining initial service units to way too much of a guessing game – risk providing too much or too little and changes are hard to make once assessed
 - Service assessments and appeals are a huge burden on service providers and families
- Service delivery should be connected to the individual costs and direct services, not lumped in with admin costs

FIRST NATIONS

First Nations participants said:

- First Nations have a very specific issue – there is no PDD funding on reserves
 - Individuals who need supports must leave reserve community in order to qualify
 - This is disruptive to caregivers and individuals who value community
 - Federal/Provincial jurisdiction issues must be worked out to ensure needs can be met
- Need for ongoing meetings with government and newly established confederacy organization to discuss on-reserve individuals with disabilities needs

NEW CONTRACTING PROCESSES

What are the most important aspects of a contracting process?

Participants said:

- Outcomes are the most important aspect
 - PDD needs to know the needs of the individual before developing goals and outcomes
 - If outcomes were clearly defined, competitive bidding wouldn't be necessary
 - If outcomes are the goal, then they should be the measurement
- PDD needs to articulate what they will be taking into account
- Performance measures need to be standardized across the province
- Co-operation to work together and support each other to make individuals lives better
 - PDD should be facilitating co-operation to ensure outcomes are met

What are things to avoid in a new contracting process?

Participants said:

- Disrupting individuals by switching between agencies
 - Yearly changes will be disruptive
 - Competitive bidding may force the end of important relationships
- Contracting process that discourages co-operation between service providers
 - This is especially important in regions like the south
- Contracts driven by the lowest cost as a goal – service has to be front of mind
- Pushing certain types of service, like family managed or large agencies, and then administering them centrally
- Centralized decision-making
 - This could lead to grouping of individuals rather than focusing on their individual needs

What are the advantages/disadvantages of competitive bidding?

Participants said:

- Advantages of competitive bidding:
 - Centralized resource to advertise services
 - No standard unit for costs for services
- Disadvantages of competitive bidding:
 - Real concern that contracts will always be awarded to the lowest bid
 - This will detract from a focus on the unique needs of the individual
 - Quality of service needs to be considered
 - The philosophy of an agency will matter less
 - Bidding could force too much change in individual's service over the years
 - This would be detrimental to fostering relationships between service providers and individuals
 - Parents in particular areas might be hesitant to send their loved ones to a different region
 - May increase administration time and costs
 - PDD will need people to deal with bidding process
 - Agencies will need to focus even more time on administrative tasks surrounding a bid process
 - There would need to be a monitoring process established for this program
 - Competitive bidding objectifies individuals needing supports
 - We worry about reducing autonomy for parents and individuals

- Families and individuals need to retain choice to go where they feel their needs can be met

What do you think about co-operation among service providers?

Participants said:

- Co-operation on services might reduce the individualization of services for some
- Co-operation on administrative work like HR, accounting and other behind-the-scenes aspects could work very well
- Concerns that some specialized services could be lost if agencies harmonize with each other too much
- Information sharing for transition between services is extremely important
 - Would like to see government departments share information better throughout the system
- Confidentiality issues that arise from co-operation need to be addressed appropriately
- Agencies already work together in this region and are willing to do it more often

MEASURING PERFORMANCE

What should be measured?

Participants said:

- Measuring the satisfaction of individuals and families is paramount
- It's also important to measure progress, not just completed outcomes
 - Recognition for being flexible and meeting challenges in creative ways need to be accounted for
- Workers should be developing their own plans with the client and then adjusting the objectives with families
 - Everyone who works with the individual should have the final version of this report communicated to them
- CET should be enhanced to focus on quality of life measurement

What should be reported?

Participants said:

- CET results should be reported in an accessible, online format
- Families need to be communicated on a monthly/quarterly basis:
 - Incidents with service providers
 - When protocols are updated or reviewed with staff
 - Information on costs

- Caregivers need to communicate directly with families about progress, outcomes and recommendations
- Professional capacities of the agencies – do they have appropriate caregivers for the right individuals and do they have accreditations
 - PDD needs to collect, hold and distribute this data

What needs to change about the system in order to become more performance-based?

Participants said:

- The system needs to have a consistent focus on individuals and their needs – how we develop the best life possible for these people
- Families need a point at where they can file complaints or concerns without fear of reprisal
- There needs to be flexibility in the service to deal with needs as they arise
- Performance measures need to be clearly defined
- Staff issues need to be addressed:
 - Staff turnover needs to be curbed in order to build relationships
 - Wages and cost of living increases need to be considered
- Clarity and common sense definitions for industry jargon – in order to communicate, everyone needs to be on the same foot

Lethbridge – June 14th

Afternoon session: Self-advocates

Summary of Key Themes Explored at Facilitation

What helps you have a good life?

Participants said:

- Good support staff/ agency
- Choice of where to live
- Having a good job
- Having good goals – things you want to have success at – makes you “feed good”
- Being independent – being able to do things along
- Safe place to make mistakes and learn from them
- Having people believe in you and appreciate your abilities
- Consistent staff – Amen!
- Access to education and lifelong learning
- Ability to do what you want – no one looking over your shoulder
- A network of friends for different kinds of support
- Being able to be honest/ maintain friendship/ keep integrity/ acceptance

What does not help you have a good life?

Participants said:

- Freedom of Information and Protection of Privacy Act (FOIP) can be a barrier even for your own files
- Overworked staff – stretched too thin
- Closed off communications with service providers. Explanation of choices helps
- Someone else making choices for you
- Being fired because of disability
- People being cruel about my disability – making fun/ making assumptions
- Misunderstandings/ miscommunication → fighting instead of finding solutions
- Lack of income. Government money does not allow for a sustainable life.
- No help in making decisions

Do you feel comfortable talking to you service provider about your supports and how well they are doing?

Participants said:

- Like to be able to share experiences with the person you are working with. Important to keep communication going
- Service providers should help inspire us...think about possibility and potential
- Disappointment can mean friendships are lost – lose self-esteem
- “We’re busy, too.” – respect my schedule/ flexibility in how PDD requirements are met
- I feel uncomfortable talking to my service provider. Can’t speak out...service provider wants to change my mind about what makes me happy
- My values and my service provider’s values might not be the same. They need to walk in my shoes. Rare to really understand me and my world
- Service providers limit us to protect their job (“move yourself out of a job.”)
- I’m scared to say so – because I want to stay where I am
- We are not products, the corporate model doesn’t work. Taxpayers don’t understand PDD

What is one thing you wish you could receive from your service provider?

Participants said:

- Money!!... into the program for good support
- More flexibility for scheduling meetings, etc.
- Get off my back. Let me do what I want to do
- Check out my home first to be sure it’s safe
- Help with exploitative landlords – need help to manage damage deposits
- Need help when I ask for it
- Help making choices
- Being listened to – two-way communication
- Know the individuals – EDs don’t understand us
- Follow-through/ help with transportation
- Want my service provider to understand my full range of skills. Acknowledge all my skills for employment opportunities



Grande Prairie

Grande Prairie – June 15th

Moderator's Summary as Delivered at the Session

What a terrific morning of insight, input and inspiration. MLA Leskiw really set the tone by communicating her commitment to listening and taking your input back to the Minister. Judy Tremaine detailed the specifics of the administrative review and set the context for your consideration about outcomes, contracting processes, and performance measurement.

When you talked about outcomes, I heard you say the following:

That being outcomes based is critically important, and the PDD funding system has to keep up with the demands that are being made on service providers. You talked about the advantages of block funding which gives service providers the flexibility to offer supports without administrative burdens. Sometimes you said, you're preoccupied with paperwork and not focused on meeting needs of the people. Flexibility rather than micro-managing services, gives the service providers a better way to go.

You also made the point that in a low-wage environment, it is difficult to get staff who pay attention to administrative details. Standards are important, but your reality is that quality staff are hard to attract and retain, and unstable staffing has a direct impact on individuals. Staff turnover has to be addressed by PDD, as does the funding implications of trying to build a stable workforce.

Money came up repeatedly in your conversations, and you said that monitoring the money is the prime focus of the contract and not the outcomes for individuals, and you said that's the wrong emphasis.

You described the current contract process as "closed" and not transparent ... and as families, you said this doesn't build trust, and it concerns you.

When you talked about employment outcomes for your loved ones, you said that the expectation restriction, of individuals being in paid employment so quickly is unrealistic. Restrictions, you said, and lack of flexibility, make working towards long-term outcomes very difficult. In the human services business, realistic expectations and patience are key, we heard.

You talked about the ideals of community inclusion and independence, and you said that PDD sometimes operates with a skewed sense of what's possible. You said, some of your loved ones slip through the cracks, and the system has to be more flexible, more comprehensive, and take into account a much broader cross-section of individuals.

Right off the bat, you said that being outcomes-based and contract efficiencies may be at odds with one another. You're concerned that choice for families could get lost and that contracts are overly formal. You also said that bidding could contribute to less stable relationships with service providers.

You said that communication is critical in the PDD business and given the changing demographics of Canada's support workers, people who can communicate effectively with individuals and with families is very important. This is related to training and professional development of staff.

When you talked about outcomes, you talked about the important distinction between care giving and skill development. As family members, you want your loved ones to learn independence and sometimes this clashes with the philosophy of “looking after” people. You also raised the point about liability and risk management. Yes, you said, we want individuals to move towards greater independence, and that may present some risks. Families and guardians may need to get comfortable with risk.

You talked a lot in the outcomes discussion about the clash between your needs and what’s available in this region and what service providers will provide and the burden of focusing on paperwork, not people. Family members expressed some frustration with the regional board, and the fact that there is inconsistency across the province, and between boards. You made it clear that in this region, given its vastness and the limited number of service providers, your unique realities – of geography and numbers – need to be taken into account.

When you looked at contracting specifics, you said any changes have to be about people not processes. You expressed concerns about competitive bidding – how does this contribute to service stability, you asked? And you worry that the idea of shared services means less individual attention for the person you love, and that makes you nervous. You said that there are already great examples of collaboration among service providers, e.g. pooling of resources to meet individuals needs. You agree that contracts that are results-focused are very important ... but flexibility goes hand-in-hand with contracts, you said. Individual needs shift and the contract must be nimble enough to adapt to the changing goals of an individual. People evolve and change course, so should contracts. You like the idea of being focused on goals, that’s the right focus, you said, and collaborative planning among all parties is key. We’re all in this important work together, you said.

The focus, at all times, needs to be on people, and any RFP process will have to be specific, personal, detailed and comprehensive. A vague, generic RFP process will not help a service provider develop a meaningful proposal. Addressing complex needs, and being able to adapt to changing needs must be a key feature of any contract.

You also made the point that privacy regulations make it difficult to know ahead of time what kind of needs individuals may have.

The public perception that every PDD recipient receives on average \$60,000 worth of service is misleading, and these misunderstandings don’t help foster community-based support for the PDD program.

You also said that while the ideal is to move individuals towards greater and greater levels of independence, needing less and less support, the reality for some individuals is that they will, in fact, need more support over time, and different support as they age.

The tracking of hours, units, codes is an example of micro-managing, you said. And while it’s intended to increase accountability, the problem is that it’s not outcomes-based and it focuses on the wrong things.

Most agencies, you said, are not-for-profits, and in order to be viable and to stay afloat, you need ultimate flexibility and the ability to move money around in order to make things work. If you are trusted, and given room to maneuver, then you are able to find efficiencies yourselves.

You talked about the PDD “clawing back” of dollars from agencies when regional boards need to save dollars. This trickle down effect of the resource problem causes agencies and service providers real challenges.

Competitive bidding certainly makes families uneasy. You said it's clinical, it's impersonal, it's too business like. You said that this is a service not a business, and corporate behaviours don't fit in a world that's about meeting individuals needs.

When you looked at shared and cooperative services, you said your concern is that there could be a lumping together of clients that might be inappropriate. You've said that previous attempts at collaboration haven't always worked. Some service providers and their boards are siloed and cannot be imaginative about bending or stretching their mandates to be collaborative. You can't regulate collaboration, you said, when there isn't a cooperative spirit to begin with. Collaboration is an attitude, you said, not just an activity – and it starts with an inclusive community free of prejudice and discrimination.

The collaboration you do see currently is that agencies already share staff, so that workers can make up their hours into a full time job. There are also examples underway of joint training and professional development. You have concerns about shared human resource functions and that confidentiality could be violated. Collaborative services have to be really carefully considered if they're going to be successful, you said.

You said performance evaluations should be ongoing, not just an annual activity. A true performance based organization, you said, does ongoing performance management, has a commitment to continuous improvement, and is very interested in hearing about the satisfaction of individuals and their families.

You also said performance measurement should not be about listing activities; it should be about meeting results. You want to know what actually changed in this person's quality of life because that's what's important to you.

You said, you shouldn't have to nag your service provider for information, reporting results should be a natural part of an effective relationship between families and service providers.

You talked about the fear of speaking up, and the reprisals that families endure if they do raise concerns. It has to be safe to complain. You said quality service is important to you, and you deserve to be listened to and treated with respect, and not intimidated.

You would like to see some ranking of service providers. If we're going to be truly effective, you said, then let's be transparent about the organizations that are not doing a good job. You talked about the importance of real honesty about incidences of abuse. Service providers earn your trust, you said, when they are straightforward when things go wrong.

Performance you said is linked to money. When services are adequately resourced they can be more effective, so you said that adequate funding is an ongoing and important factor in this conversation.

Performance measurement has to be based on goals. So that cycle of good planning, great service delivery, and transparent reporting is important to you. All these factors have to be in synch, working together, from a trusting relationship base. There are those words again “relationships and trust”. This is key for you, and is the basis of great service.

You want meaningful information reported to you about how an individual is doing, and you want your service provider to be able to share data with you.

There’s a complication here though – adults with developmental disabilities have to consent for their information to be shared, so the delicate balance between rights and regulations and relationships has to be preserved.

And you want performance measurement to actually have an end result if nothing changes after feedback is given. What’s the point of the feedback, you asked? Continuous improvement, as opposed to lip service, is about responding and changing based on data.

Service providers mentioned that sometimes it’s hard to get families involved, and so being in partnership with families can sometimes be difficult. Ongoing reporting to individuals is a show of respect you said, and helps them to see how they’re progressing against their goals.

The concept of communication was a theme threaded throughout this morning. You said it’s vital to an effective system, it’s respectful, it’s trust based and it’s non-adversarial. You said that any future enhancements have to be well thought through, well communicated and managed in a respectful way.

Just a reminder that nothing is going to change quickly and nothing has been decided already. Your wisdom today, and it was considerable, will shape the future of improvements in the PDD system.

Thank you for your help Grande Prairie.

Grande Prairie – June 15th

Morning Session: Family members and service providers

Summary of Key Themes Explored at Facilitation

BEING OUTCOMES-BASED

How can service providers and contracts enable an outcomes-based focus?

Participants said:

- Contracts need to allow for flexibility in individual outcomes – don't take a cookie cutter approach
- We need standardized support for staff, like training programs to develop core competencies and advanced skills
 - This is something the government needs to provide, not something the agencies need to develop
 - Consider reviving rehabilitation education programs at universities and colleges – market the profession
- If there is an emphasis on the monitoring financials, or a view on the bottom line, we risk individual needs getting lost in the system
- Parents should be involved, but not always depended on
 - The system will need to be able to assess needed outcomes as parents age
- Service providers need to know what outcomes they need to report on across the province

What's getting in the way of being outcomes-based?

Participants said:

- In such a small region, families don't always have a lot of choice for services
- Government needs to establish a monitoring and accountability system for service providers
- Family Managed Services are not easy to provide, be careful when asking families to take on so much responsibility
- Government departments need to coordinate more, especially on medical issues

NEW CONTRACTING PROCESS

What are the most important aspects of a contracting process?

Participants said:

- Contracting processes need to clearly define the expected results from service providers
- Performance measures and evaluations assessments need to be defined

- Both of these need to be defined across the province
- Co-operation is important, but there must be guidelines on how to share services like HR, accounting or even staff between agencies
- Contracts need to reflect the flexibility required to ensure that individual needs are always being met

What are things to avoid in a new contracting process?

Participants said:

- A move to big agencies may represent the elimination of choice for many families
- Shorter contract periods may make it harder to keep staff
 - Changes in staff due to the contract renewal process may be detrimental to individuals getting supports, and are hard on families
- Contracts need to avoid an over-reliance on financial and service unit tracking make service providers administration heavy
- Competitive bidding a concerning process

What are the advantages/disadvantages of competitive bidding?

Participants said:

- Advantages:
 - Could encourage co-operation among large service providers
 - Some administrative efficiencies could result
- Disadvantages:
 - Uneasy about the idea of “bidding on people” – this is about people and their unique needs
 - Some clients are too complex to be lumped in with a whole group
 - Continuity for individuals could be disrupted by service provider not successfully bidding
 - Concerns that the best process will pick the lowest bid, not the best bid

What do you think about co-operation among service providers?

Participants said:

- Co-operation is a good idea, many agencies are already doing this in our region
 - PDD needs to recognize when we do this effectively
- Co-operation can work, even with other non-profits in the region

MEASURING PERFORMANCE

What should be measured?

Participants said:

- Satisfaction of parents and individuals and individual growth should be a priority measurement area
- Agency information should be measured:
 - Satisfaction surveys
 - Staff turnover
 - Reasons for client exits
 - Whether agencies adhere to best practices
- Ability to deliver on outcomes laid out in the original contract

What should be reported?

Participants said:

- Daily/weekly/monthly logs of activities and progress for individuals should be given to families
 - They should include other appropriate information such as medical data
 - These should also be available to the individual, too
- Reports of what, within the service plan, is not working for the individual
- Service provider budget information
 - How much of their funding is going to administration
 - How much funding is the service provider getting
- Periodic information about the performance of PDD as a system
- Agency accreditations need to be front and centre

What needs to change about the system in order for it to become more performance-based?

Participants said:

- Improved communication with families – this needs to be consistent across the province
- There needs to be an advocate you can call to address issues
- Service providers need to help lay out appropriate expectations about what are good decisions rather than telling families what to do
- PDD coordinators need to be attentive, available and honest with families to help them set realistic expectations
- PDD needs to be more fair to agencies – they cannot always afford to eat costs or deliver on retroactive payment
- Move away from the focus on paperwork
- Act on the personal needs of families and individuals

Grande Prairie – June 15th
 Afternoon Session: Self-Advocates
Summary of Key Themes Explored at Facilitation

What helps you have a good life?

Participants said:

- Family
- Being able to honour my ancestry/ heritage/culture
- Going on trips buying what I want/like
- Good friends – they help me
- More support in High Prairie
- Getting a job – employers who understand a job coach and what I need to learn
- Being appreciated
- High Prairie gets “lost” – I want a chance
- Smaller communities need support like cities
- Small communities getting together
- Money for going to medical appointments
- Transportation/ gas, etc. → too expensive
- Salaries for staff should be the same across the province
- Support from the community
- Being able to do crafts

What does not help you have a good life?

Participants said:

- Loss of family/friends is tough
- Illness
- Losing community support worker is difficult – staff change
- Not enough money for time with workers

Do you feel comfortable talking to you service provider about your supports and how well they are doing?

Participants said:

- Difficult to ask for what I want – want more support → people don't listen to me. Sometimes listen/ sometimes not
- Don't always believe me when I am sick

- They do adjust things for me
- Sometimes I want to learn more and I don't get a chance
- Too afraid to speak out. Nervous
- I can talk to my workers – it's easy.
- It's easy when there's a good relationship/ get along
- OK to talk to agency/ workers
- What is tough is the annual service plan when I want a worker change...defensive/ change the subject. Bring it up but gets swept away
- Hard to know what to do next to make my opinion heard
- Sometimes my worker listens...not all the time. Easy to talk

What is one thing you wish you could receive from your service provider?

Participants said:

- Do things together with support worker
- Have staff stay – might not be realistic
- Being able to take flowers to cemetery (“Doing what I want!”)
- Would like to go back to school or study at home
- More opportunities for crafts
- Workers allowed to support us in more activities/ volunteer stuff/ more variety. Come to volunteer activity with me to support me – but the rules don't allow it
- Make lots of stuff. Build things to sell
- More trust
- See family



Calgary

Calgary – June 20th

Moderator's Summary as Delivered at the Session

What a nice morning of discussion. I know it was warm in here and I know it was noisy, and despite that you gave us some really great input that is extremely valuable.

When you talked about being outcomes-based, I heard you say that what's key to positive outcomes is well-trained and highly skilled staff. The front line workers need more and better training on what it means to support an individual in attaining their dreams. Administering mediation is one thing but knowing how to support aspirations is a very different skill set.

You said that staff members are not always as client-focused as they should be.

You also said you want access to information about your loved ones. Some of you said that you don't feel sufficiently "in the loop" about the plan for your loved one.

You talked about the importance of professionalism ... and how the caliber of staff really makes a huge difference to your PDD experience.

You said that while PDD is your funder and meant to be your ally, when you do have issues with your agency, PDD should help broker that relationship and have a mechanism for solving problems.

Some of you in family managed care expressed frustration that there are real challenges being able to attract and retain staff on low wages. It's very difficult, you said, to put stable and consistent staffing in place when you can't match agency salaries and have no incentives to offer staff.

You talked lots about the challenges of attracting skilled workers into a low-wage sector and that this represents a big stumbling block to being outcomes-focused. Staff who work in an outcomes-based way is critically important to you and tough to find, keep and advance.

We heard from one service provider that manages to keep staff effectively, but find themselves subsidizing payroll through fundraising initiatives. Their problem is different from many; they pay more, they keep people, they are promoted within the agency, but it represents financial sustainability challenges.

I heard you talk about seamless delivery of service, and how important that is for individuals. You said paperwork and administrative burdens and coding hassles really get in the way of getting what you need, when you need it. Let's simplify the processes, you said.

You talked about the important cultural shift that PDD has to undergo to really embrace the notion of being outcomes-based. Enough reports, enough process reviews, what's really required is a commitment to major shifts in culture to be focused on quality services, a results orientation and performance measurement excellence. Let's not tinker around the edges of contracting, you said, let's commit to the big changes that will really matter.

You said that the system is focusing on managing money and documenting its flow, and isn't as focused as it should be on the real bottom lines, which are meaningful and inclusive lives for people with developmental disabilities. Contracting, you said, is about good long-term planning and assessment that looks at a life span while integrating of services across a spectrum.

When you talked about contracting specifics, you delivered some very strong messages. I heard family members say – you cannot commodify my loved one by making them a cog in the contracting process. We're talking about people here, you said, and the business processes of competitive RFPs didn't sit well with many of you.

Some of you had questions about the validity of the KPMG report and its definition of administration costs, and you said that the questions and issues that the report raises may not, in fact, be the most important ones for you. Your perspective is welcomed, and we're glad you shared it today.

You expressed your concern about shared service provision and said you are worried that PDD wants to lessen the number of service providers in this region from 40 plus to a smaller number and the implications of this direction are worrying for you.

You said any contracting process has to be completely focused on quality staff. That's your bottom line – staff make all the difference. Any contracting process has to focus, first of all, on quality.

Parents, you said are the most important decision-makers on contracts ... and any removal of parental choice on decision-making for many of you would be a big problem. Parents and family members, you said, should have the ultimate decision-making authority.

I think I heard *"it's the immediate staff that count"* dozens of times. Their relationship with the individual is pivotal, and so for you, the move towards competitive bidding is at odds with being outcomes-based and represents further administrative burdens – not fewer. *"We're not building a house here, we're building lives."* You said, the kind of instability that competitive bidding represents for you is very detrimental to individuals, and the competitive aspect of RFP processes will detract, you said, from collaboration among service providers. It will pit you against each other, and it will contribute to staffing instability and general insecurity within the sector. Many of you said that competitive bidding will be a damaging direction to go in. You really want PDD to think about this. In fact, you said, given the climate of fundraising that many agencies operate within – there could be savings lost, not gained. You said, you currently subsidize PDD funding through philanthropy, and in a competitive environment, this would be lost.

While there are many aspects of contracting reform that you like, such as clear outcome identification and performance measurement – you are really unsure that competitive bidding will save administrative costs.

Numerous times, I heard you say that a competitive process that loses sight of parent voice and choice is very worrying for you. You are nervous that no savings are guaranteed and a lot of parent autonomy could be lost. Too big a trade off, you said. Competitive bidding you said, does not foster collaboration, it creates an insular system that won't share and is too afraid to cooperate; you said, this is at odds with the spirit of collaboration, shared outcomes, performance excellence, and "all of us being in this critical work together."

The word "assessment" came up over and over again, and you said competitive bidding might actually discourage service providers from taking on clients with complex needs. Skimming off the "difficult cases", you said, is one way to make an agency look efficient, but you really don't want to go down that road, because the system should be person-focused not process-focused.

"Tendering out" homes, you said, is inappropriate, it goes against the deeply held philosophies of client's stability, inclusion and building better lives. While you said that accountability and good processes are key, tendering a person's life strikes you as problematic.

You want defined outcomes, efficiency and clear performance accountability but you're not sure about the complete package including competitive bidding. Parts of the business model work, you said, but perhaps not all.

When you considered shared services from one contract provider, you delivered this clear message. "Bigger is not necessarily better". Bigger organizations risk being remote and more bureaucratic, less personal; and in the people business, this is a real risk.

You had a very robust – dare I say, spirited – conversation about contracting specifics, and your bottom line was "be careful." You said, we're not even sure that the premise that the system needs fixing is a sound premise. Perhaps we're in better shape, you said, than the KPMG report suggests.

When you moved on to talk about performance measurement, here are some of the things that I heard. You said you want to know a variety of things about your service provider, primarily around individual family satisfaction. Surely, you said, job number one is working with individuals and families to ensure that needs are met. When they're not, some of you said, parents should have their own ombudsman to field dissatisfactions and broker solutions; an impartial problem solver that really hears your concerns.

Measuring satisfaction, you said, is key, and you want agencies to be creative in how they do that. Everything else stems from satisfaction. And performance has to be closely aligned with the outcomes identified.

You said performance monitoring has to happen at both a macro and a micro level, and needs to combine both formal and informal reporting. You said, performance measurement is not a point in time – it's an ongoing process that needs to be properly documented, and tied to identified outcomes. Excellence, you said, cannot be ad hoc, it must represent a real commitment to improved results.

Performance measurement has to be flexible and agile. Plans change, you said, performance measurements have to match what's really going on. Adjustments and course corrections along the way are important to you.

Performance measurement, you said, has to be meaningful. Processes that look like performance excellence, but are in fact, paper exercises that don't really matter are of no interest to you.

You said that it's very difficult to have a meaningful handle on the lives of individuals. Reporting performance for 9,300 individuals in a way that's meaningful is really tough.

You said the PDD system needs to have clarity about roles and responsibilities. You are not interested in a system where agencies and families are micro-managed. PDD, you said, needs to get back to its core role, as an impartial funder and be a "good bureaucratic organization." Some of you said that PDD is clear about its role, and gets out of the way of the real relationship that exists between families and front line service providers.

The concept of an impartial advocate for families and individuals came up more than once. Call it an ombudsman or an advocate, a number of you said that for this system to be more performance-based there, has to be a safe, effective, and independent way to voice concerns and have them resolved.

You talked about regional inequities in funding across the province and the fact that all regions are not funded equitably.

Money came up a lot – you said it is the root of driving positive change – more resources to do the important work. CET, you said, is a blunt instrument for measuring performance, and you'd like to see a more sophisticated tool for determining quality service provision.

Trust, you said, is critical, if this is lacking, then any performance measurement system is mere window dressing. You were very clear that a better system for individuals begins with a healthy culture of trust and mutual respect. The word "relationships," and the importance of them, came up over and over again.

Those of you in the family managed services end of things made the point that you really do a lot of work, and your sweat equity is not really taken into account as an administrative cost.

It was a very rich discussion. Thank you, Calgary.

Calgary – June 20th

Morning Session: Family members and service providers

Summary of Key Themes Explored at Facilitation

BEING OUTCOME-BASED

How can service providers and contracts enable an outcomes-based focus?

Participants said:

- Service providers should and do focus on individuals and how they are satisfied
 - We can't do this without hearing from the family and the individual getting the supports
 - How families will be involved should be included in the contract
- Flexibility in contracts is a must
 - Clients are complex and their needs (eg, health) change over time – contracts need to reflect an ability to make changes to best serve those unique needs
 - Flexibility is the best way to see results on long-term goals

What's getting in the way of being outcomes-based?

Participants said:

- Contracts need to be set up to go beyond one year – long-term contracts will help make meaningful progress
 - Our goals can't all be achieved in a single year
 - Short-term contracts destabilize agency goals
- Contracts focus on dollars, not appropriate levels of service
- Need to find a balance between overburdening of paperwork and the accountability those checks provide – system can be focused and accountable
- Low staff skill-levels and high turnover impacts outcomes for individuals
 - Consistency in staff is a direct route to achieving better results and developing specific outcomes
 - Competing for staff at agencies is a constant struggle because of low wages
 - Pay within industry needs to be standardized so agency workers can be brought up to par with government staff
 - The cost of constantly retraining staff due to turnover probably costs more than paying more in the first place
 - Difficult to find professional staff
 - Some still require foundational training, let alone professional training
 - More than a high school diploma should be needed

- Money for training staff is unavailable or small
- Worried about what effect an overheated economy will do to the availability of staff
- Family managed service providers are at the bottom of a two-tiered system with funding – keeping staff is even harder than for agencies

NEW CONTRACTING PROCESSES

What are the most important aspects of a contracting process?

Participants said:

- Clear expectations of outcomes are important if we're going to serve 9300 properly
- Contracts should ensure that choices are available to match individual needs
- Free co-operation between agencies rather than competition
- Flexibility to accommodate changes in the needs of individuals and in the workload of agencies
- Build contracts that create consistency for clients

What are things to avoid in a new contracting process?

Participants said:

- Goals and outcomes dictated by funder
- Commodification of the needs of PDD clients
- Focusing on delivering consistency in service for individuals
- Competitive bidding system where lowest cost is the most important factor
- Reducing service provider choices for individuals/families
- Competitive bidding would only work for a small portion of what we do

What are the advantages/disadvantages of competitive bidding?

Participants said:

- Advantages:
 - There are some efficiencies for agencies and PDD
 - Properly set up, competitive bidding could weed out service providers who aren't working well
 - Sets up quality standard for all the regions
 - Service providers could cooperate to bid on the "true cost" of services
- Disadvantages:
 - Losing agencies because they don't have resources to write good proposals

- Agencies that don't get donations or do fundraising won't be able to compete with those who do
- May pit agencies against each other – discourages co-operation
- RFP's work for short-term projects, not long-term
- Funding will be tied to agencies, not people
- Smaller agencies may not survive
 - This may eliminate some specialized service providers
 - Complex needs may be unattractive to agencies that can bid on larger contracts
- Creating larger agencies may move away from unique needs of individuals
- May force a change in service provider for an individual – this can destabilize individuals receiving care
- May take away the power of parents and individuals to make decisions about care

What do you think about co-operation among service providers?

Participants said:

- Collaborating and interconnected agencies can help find appropriate care for unique individuals, even if they can't provide it themselves
- This can't work in conjunction with the competitive bidding process – they are opposites
- Could work for agencies to share accounting, professional services, and education for front line staff
- Excellent potential for information sharing between agencies, including client info
 - Need to be careful with privacy rules

MEASURING PERFORMANCE

What should be measured?

Participants said:

- Satisfaction of the families and individuals receiving supports
 - Get input on what is working and what needs to be changed
 - Keep measurement focus on the client, not the system
- Don't look at just a single year – measuring progress over a longer period of time is important, too
- Measure staffing at agencies
 - How many staff and how much are they being paid
 - What kind of resources are being put into staff training

- How is staffing changing at an agency
- Level of communication between service providers and clients – formally and informally
- Flexibility – if the service provider is able to change when needs change

What should be reported?

Participants said:

- Reports on unannounced visits to determine true quality of service provider
- Level of regular contact with parents and guardians
- Service providers need to be open
 - Reports from workers to service providers need to be available to guardians and clients
 - Response times for agency to clients
 - Administration and budgeting
 - Staffing statistics

What needs to change about the system in order to become more performance-based?

Participants said:

- Families need a neutral party to help navigate system
 - Helpful for resolving issues or for asking difficult questions
 - Need a system where they can feel safe providing constructive feedback
- PDD needs to define their role in the system and work to build trust with other stakeholders
- More funding to assist with training front line staff and salaries to retain those staff
- Address regional inequity
- Service models need to be addressed in a more specific way than CET can

Calgary – June 20th

Afternoon session: Self-Advocates

Summary of Key Themes Explored at Facilitation

What helps you have a good life?

Participants said:

- More personal contact with people/ building relationships
- Doing things together. e.g., help with shopping.
- Being able to learn skills
- Being in environment where focus is on learning
- Workers who are really focused on the individual
- Do what “I want”
- More interaction/ growth/ learning
- Service provider focused on me
- Focus on things I can do – not what I can’t
- “Always there for me.” Good relationship/ knowledgeable person
- Home: safe and secure place to live
- People understanding my disability
- “Ideas”. Inspiration. Aspiration.
- Being really engaged – with “heart”

What is a Barrier?

Participants said:

- Ignorance
- Explaining myself, not understanding needs
- Hidden disabilities
- Disrespect of my needs
- Lack of affordable housing
- Lack of accurate assessment
- Being isolated
- SIS is intimidation (but useful)
- Having to appeal to get what I need causes anxiety/ mental health issues
- Confusion – jargon/ plain language
- Not having an advocate to support me as I appeal/ explain.

- No one to talk to about my problems
- Friends/ not a lot of people you can trust

Comfortable talking to service providers?

Participants said:

- Sometimes it is hard.
- Worker not focused on safety. Didn't follow procedure.
- Don't know my daughter's needs after 10 years.
- Quality of service has gone down. Agency did listen after the crisis.
- SIS is a help to identify needs
- Service provider does not ask how well they are doing
- Can talk to service provider. Very happy with care.

What is one thing you wish you could receive from your service provider?

Participants said:

- More understanding
- Help identifying what you want/ need to feel good about life
- Clarity
- More time to follow through on my ideas
- Transit access
- Service provider or anyone to advocate for transit
- Good care giver – well-trained people
- More funding
- Quality service → not just about the money
- Don't want to waste government money
- Stop funding inequality between individuals
- Evening hours/ flexibility/ able to go out at night
- Help advocating for change



Edmonton

Edmonton – June 21st

Moderator's Summary as Delivered at the Session

What a great discussion we had together today... your contributions were rich, diverse and very helpful. Thank you for your very high caliber contributions.

When you talked about being outcomes-based, I heard you say the following things:

What families really need is to be involved in setting goals and defining outcomes. Families are experts in their loved ones' lives and their insights are critical in the planning and assessment part of setting outcomes. You also said that outcomes aren't always played out well by the services provider's workers. There needs to be closer monitoring of the way outcomes are met, and it comes down to the quality of care at the front line. Family members mentioned that retaining quality staff is difficult.

You talked about the importance of balancing parent perspective with service provider input, so that you plan together in an atmosphere of mutual respect.

You talked about the wage discrepancy between PDD government workers and community service providers. This significant percentage difference makes for a very uneven playing field, you said, and causes all kinds of problems that you said must be resolved.

You talked about lifelong learning being a key element of being outcomes-based, but you said it's tough to find opportunities for ongoing learning for your loved ones. You said our communities need to be creative about seeking out these learning opportunities. Tapping into individual's potential through learning sometimes needs to be explored more fully.

You talked about the frustration of not being listened to as family members when you want to connect with service providers. You talked about the power balance – service providers and PDD "in charge" as opposed to families being in the driver seat. This power balance needs to be redressed, you said.

You expressed frustration about not being able to reach your PDD worker – full voice mail boxes, tardy return calls and you said you'd really like to have better customer service from the funder – because this is your money – the taxpayer's dollars – that is being used. Some of you said that you feel obstructed in reaching people, and it contributes to a lack of trust, and creates challenges in building an atmosphere of mutual respect.

You talked about the challenges of finding staff when you are in the family managed system – you feel you have to take what you can get – and this lack of quality staff really detracts from working in an outcomes-based way.

You said, this quality of staff issue is directly related to the low wages in the sector, which makes it really tough to attract good people.

You talked about dollars a lot, and the fact that inadequate resources really detract from being outcomes-based.

You talked about the disconnect between families/service providers and the PDD regions. You said these three entities have to work well together and currently they don't always operate as cohesively as they should. You gave us an example that the SIS is an academic instrument that families cannot relate to. Let's come together with plain language and common sense, you said.

As you talked about contracting elements and specifically competitive bidding, you said you're concerned about the instability that competitive bidding represents. You said it's tough for families who don't know whether contracts will last, and tough for staff and agencies who don't know how long their jobs may last. I heard you say: "if PDD wants to be like a business and use business practices like an RFP process, then it has to stop interfering with the business of service providers". You said there's currently considerable micro-managing which is at odds with excellent outcome-driven business practice.

You expressed many cautions about competitive bidding, while it can increase accountability, you said the "for profit" motivation in competitive bidding is troubling for you in a people business like PDD.

You said you weren't entirely confident that "lowest cost" wouldn't emerge as the criteria for winning a bid. That's a fear for you, because dollars are only one factor in quality service, and certainly not the most important, you said these business principles might be at odds with the compassionate care necessary for successful service provision.

You said, continuity is key, the ability to stay with the same service provider over time. The individuals you care about value consistency, familiarity and stability, and competitive contracts are at odds with this important stability.

You talked about the fact that shared services run the risk of eliminating choice. Already parents voice and choice get easily lost and you aired concerns that if service providers are collapsed, or amalgamated, you have even less say, and less choice, in who offers service for your loved ones. Parents have to stay a part of the decision-making in competitive bidding.

You said that competitive bidding and service provider collaboration are at odds with one another; one could cancel out the other in your view.

You also said that service provider co-operation looks different in rural or urban Alberta, and those distinctions need to be carefully thought through.

You asked whether there is enough joint understanding among service providers to really collaborate effectively. Right now, you said, you're not sure that agencies have enough knowledge of each other. And you asked where the real administrative savings lie, is it in purchasing power, you asked?

For you – when it comes to contracting in a more coordinated fashion, you said the bottom line is to be outcome driven, and focused on results. You said that there is the potential for less confusion and less administrative headaches for you as parents, through collaboration.

When you talked about performance measurement, you said, this cannot just be a paper exercise ... it has to be about really paying attention to the happiness of individuals. You said that this is not easy, but performance measurement has to be creative, subtle, and sophisticated enough to really find out whether an individual is having a meaningful life. You said that tangible, day-to-day insights are so much more important than a one-off paper exercise.

You said, performance measurement has to be ongoing, it has to be consistent and it has to be people focused. This conversation once again came back to quality staff. When good things are happening between support workers and their clients, you don't need a really oppressive monitoring system.

Units of service, you said are about counting and following the money, but they're not about measuring outcomes. If the system wants to be really focused on excellence, then measuring the right things is key.

You said satisfaction of families and individuals is probably the most important driver of service provider measurement.

And you said you want information about service providers made public, so that families are empowered to make choices among agencies. However, you cautioned that some agencies might be reluctant to share information or take complex clients who might diminish their performance "scores". Some of you said this sharing of performance data should be done by PDD, and others said this information should be shared transparently by agencies. Where you did concur is on the topic of that having easy access to performance data. As families, you have the right to know how your service provider is doing. Information, you said, is power.

You also talked about the importance of individuals themselves having a say in performance measurement ... let's ask the clients, you said. They can be very clear about what's working and what's not.

You talked about the importance of the evolution of quality service, working with an individual over time alters what happens ... and so the performance measurement framework has to be flexible and agile enough to look, not just at a point in time, but at a lifetime – with all the changes that take place.

Performance measurement is important, you said, it has to be personal, intimate, and long-term. It cannot be superficial, and it cannot be an agency popularity contest.

It was very valuable input, offered thoughtfully and generously. Thank you Edmonton.

Edmonton – June 21st

Morning Session: Family members and service providers

Summary of Key Themes Explored at Facilitation

BEING OUTCOME-BASED

How can service providers and contracts enable an outcome-based focus?

Participants said:

- Families are critical throughout the planning process – they know their child better than anyone else
 - Families can help the service provider determine what their individual needs and stated outcomes should be
- Defining outcomes need to be based on the how the person has benefited, not on the delivery of the service
 - Outcomes need to be based on what is actually done
- Flexibility in contracts allows outcomes to be redefined when conditions change and approach with individuals must be taken differently

What's getting in the way of being outcome-based?

Participants said:

- A lack of coordination and co-operation keeps families from bringing forward their input
 - Families can't build trust and mutual respect without available communications avenues – frustrated their input isn't being heard
- Families don't feel free to bring up issues
 - Worried that they will lose supports as a result
- Without a commitment to staff, there is no staff commitment
 - Government staff are paid as much as 35% more than agency staff
 - This disparity needs to be corrected province-wide
 - Good staff are difficult to keep due to low wages
 - Staff retention is the best way to establish relationships
 - Inexperienced staff that aren't trained properly can't engage individuals in challenging activities they might want to do – ie learning-based activities
- Because PDD restricts family managed salaries, staff are even harder to retain in family managed care
- Programs like SIS aren't evaluating unique client needs, people are getting pigeon-holed

NEW CONTRACTING PROCESSES

What are the most important aspects of a contracting process?

Participants said:

- Family choice need to be taken into account
- Families should be part of a competitive selection process or at least be educated on how the process works and what input they'd have
- Clearly defined outcomes should be comparable province-wide
- Need to define what counts as administrative costs and what counts as operating costs
- Vital need for flexibility in contracts to react to changing needs

What are things to avoid in a new contracting process?

Participants said:

- Cost can't be the major determining factor – the ability to provide for unique needs must come first
- Competitive bidding may create anxiety about service reductions for families and staff
- This is a human service industry; it's not a typical business and a business-like approach might not apply
 - A “for profit” motivation won't work with a system trying to satisfy individual needs

What are the advantages/disadvantages of competitive bidding?

Participants said:

- Advantages:
 - Healthy competition could eliminate some complacency
 - Opens new opportunities for transparency within the system
 - Allows agencies to cooperate
- Disadvantages:
 - Competing with other agencies will change their services
 - Staff may lose some job security – prevents long-term planning
 - Competition could threaten the consistency of our care
 - Staff consistency is very important to the quality of our care
 - Adds more admin-type work to agencies
 - Agencies need will need hire people to do procurement
 - Lowest cost may ultimately become the bottom line

What do you think about co-operation among service providers?

Participants said:

- Service providers have a lot they can teach each other about best practices
- Co-operation between urban service providers is very different than co-operation between rural service providers – be careful about mandating
- The ability to make choices needs to remain – clients with complex needs require choice to get the best care
- Concerns that amalgamation of services will reduce specialized services
- Sharing care of a client could work, but it means that PDD needs to allow agencies to be flexible with money

MEASURING PERFORMANCE

What should be measured?

Participants said:

- Measurements need to go beyond paper metrics – need to know if the client is actually engaged in their care
 - Clients need to have a say in their care
- Ability for clients and parents to provide input into how care is delivered
- Focus measurements on actual client outcomes:
 - Satisfaction and happiness of their needs and wants
 - Client progress on the outcomes
- Measurements need to be flexible to react to changing needs of clients
 - We should approach measuring performance as a moving target – respect that care is a long-term goal
- Measuring intangibles will never be exact, but it's something all stakeholders can work together on
- Accountability for service units are important, but they shouldn't be the focus of what we measure
- Levels of staff satisfaction

What should be reported?

Participants said:

- Regular communication to families at a rate the family is comfortable with
 - Families shouldn't have to chase down information
 - Care givers opinions are important, they need to be listened to

- Description of what goals are met and how adjustments can be made to meet future goals
- Transparency on administrative side:
 - How is money being spent?
 - Agency accreditations
 - Incident reports (or at least the quantity)
 - Staff turnover rates are key – building relationships matters
- Information on agencies and what services they provide
- Information reported needs to be easy to access and centralized online
- Best practices in regions and among agencies

What needs to change about the system in order to become more performance-based?

Participants said:

- Culture of making ends meet and of survival needs to give way to a culture of innovation. Then we can focus on goals
- Funding needs to be linked to individuals and what it takes for them to have a good quality of life
- Clarity in the roles of all the stakeholders in PDD
- The process of changing services and outcomes-based on evolving client needs should be simple from both a service provider and funder perspective
- There needs to be a neutral party so that clients and families can take action in the system without fear of reprisal
- We need a team that works together to plan for the individual – a big part of that is communication and collaboration
- Create family-managed care resources centres like the one in Edmonton across the province

Edmonton – June 21st

Afternoon: Self-Advocates Session

Summary of Key Themes Explored at Facilitation

What helps you to have a good life?

Participants said:

- Knowing that the supports are there when you need them
- Being able to live in a group home and having someone else other than family take him places
- Amazing to find a good employer. He's been very fortunate. Same job for 20+ years
- Have a worker that comes to check up once in a while and to see how I'm doing. (Support worker ensures you're doing okay, on the right track.)
- People that I serve on Fridays are like my second family. Have been there for 10 years. Volunteering, without it would feel lost
- Doing things on my own without people telling me what to do
- Having good friends
- Being in the self-advocacy federation
- Being part of a group of peers

What doesn't help you to have a good life?

Participants said:

- Staff should listen to us instead of just citing regulations and protocols that we don't understand
- People who don't try to understand us – we worked very hard to get where we are and want to be well treated
- Pushing you to volunteer when they are there to help you find employment
- People jumping to conclusions; major stigma in society. Some employers – as soon as they see the wheelchair, they think there's nothing going on upstairs
- Support staff that comes in and takes over even though we can do things on our own. Very frustrating in your own home
- People who won't help you be your own guardian
- Disrespectful staff that are always focused on themselves
- Staff not listening to you about what you want

Measuring performance – do you feel comfortable talking to your service provider?

Participants said:

- Yes, but haven't. Getting up enough confidence to go to them and say what's wrong

- Most of the time – sometimes not, just depends on how I feel. If I don't like something, I say it to my support worker who takes it to my service provider
- Yeah, I do. If it had anything to do with what's going on with work, I would
- If you get laid off, they have a relationship with the employer, they will come with you and help with the transition, and it's their duty to find you other work
- I worry about what they are writing about me and what they are doing with that information. I want an open system
- Family-managed supports – she does the hiring and firing. If any of us have any issues, we go through her. So it's much easier to go through her
- Well, my last staff, no I didn't. But my new staff I'm pretty comfortable. She asks me what kind of supports I need and I tell her what I need and talk to her about anything
- Speak very highly of them. Worker really helped me in the work world. I can advocate for myself, but with a serious problem, I can always go to them

What is one thing you wish you could receive from your service provider?

Participants said:

- Respect.
- More services to help with your special needs
- Honesty
- More hours
- Let me speak for myself, let me do what I can
- To have my key worker always come and check up on me. Come and just see how I'm doing. Check up on me at work
- Autistic people like regularity. As soon as things change... You have to let them know
- Communication with more information – feedback more from the agency – even if it's a newsletter or something, letting us know what we could access
- Information on recreation, like a recreation guide. Like to know what programs are out there. What opportunities, like swimming, drawing, painting
- Put our stories on the news



Written Submissions

We would like to acknowledge and thank the many individuals and groups who submitted written statements for this process. We have summarized those submissions into key themes as with the other sessions. However, we have chosen to omit detailed personal stories and circumstances for the purposes of privacy and discretion. All written submissions were reviewed by MLA Genia Leskiw.

Summary of Key Themes Arising from Written Submissions

Family Members and Service Providers

BEING OUTCOMES-BASED

How can service providers and contracts enable an outcomes-based focus?

Written respondents said:

- Limit FMS agreements to 36-month term with an annual review only for the financial portion – maintain accountability but still focus on long term goals
- Use contracts as a tool that can be used to flow funding to yield good outcomes
- Using a corps of contracted service providers to coordinate services, negotiate contracts with other providers, coordinate with community representatives, provide administrative support and regional leadership
 - Having this group report to regional boards as opposed to reporting by the regional CEO would ensure that the boards allows reports that better reflect the true conditions on the ground
 - This will help regional boards be more responsive to regional needs

What's getting in the way of being outcomes-based?

Written respondents said:

- Allow parents to have input into what the service provider contract outlines as outcomes – I know my child better than PDD does
- There is a lack of understanding as to what is funded and what isn't funded by PDD
- Emphasis on contract and administration monitoring and reporting is eroding the philosophy of individual supports
 - There is too much of a focus on the financial aspects of delivering supports
- Expectation of staff are unrealistic
 - The rules that limit their behaviour don't make sense in the context of caring for someone and establishing a relationship with them

NEW CONTRACTING PROCESSES

What are the most important aspects of a contracting process?

Written respondents said:

- An approach that allows PDD to have some involvement in the planning conducted between service providers and families
 - Should foster continued opportunities between PDD and service providers
- Should strike a balance between quality services (including accountability measures) and ensuring good results for individuals
- Ability to audit achievement outcomes as well as financial benchmarks

- **What are things to avoid in a new contracting process?**

Written respondents said:

- One-formula-fits-all found in competitive bidding has the potential to damage progress
 - This is not a population that reacts well to change
- Automatic agreement renewal
- System-driven approach when a people-driven approach is required
- Any provisions that prevent or discourage agencies from working together in the same regions or communities
- Care for an individual by a family member should not be prohibited

What are the advantages/disadvantages of competitive bidding?

Written respondents said:

- Advantages:
 - Could be useful in a day supports or employment supports context
 - There is some opportunity for families to be involved in the selection process
 - Possibility for some administrative efficiencies in service delivery
- Disadvantages:
 - Administration workloads are already overburdened; will they be able to handle making RFP decisions?
 - Cash-strapped agencies would need to hire a staffer to write proposals
 - The quality of service will decline with the costs
 - PDD service workers are not interchangeable
 - They will need new training and resources to get up to speed
 - May limit families choices for service providers
 - May force changes to service providers – a potentially detrimental prospect for individuals
 - May increase staff turnover rates as a result of failed bids
 - Worries about reducing the care of individuals to a bid

What do you think about co-operation among service providers?

Written respondents said:

- Sharing staff training and accounting services would work well
- Sharing service delivery resources will lead to congregation and segregation of individuals
- Common training programs could save admin costs
- The larger an agency gets, the further away clients get from making any decisions

MEASURING PERFORMANCE

What should be measured?

Written respondents said:

- Satisfaction of individual and family
- Not the satisfaction of families (too subjective)
- Ability to lead on best practices within the system

What should be reported?

Written respondents said:

- Improvements over the last year, POI results, all financial matters

What needs to change about the system in order to become more performance-based?

Written respondents said:

- A client advocate for each region could help clear up confusion and misinformation
- Move to longer-term contracts
- Teach staff to understand, not just deal with individuals
- Increase emphasis on formative evaluations focusing on continuous improvement
- System needs to ensure that it is positioned to care for individuals in the best possible way when their parents or guardians are gone
- Adding direct service wage increases will reduce administrative spending
- PDD needs to plan and document our present/future purpose/mission statement
 - We need to work together to establish it, communicate it and review it annually
- Consider whether the assumptions of the KPMG report are even correct
 - There is a clear definition of administration – there isn't
 - One service provider is best – this assumption eliminates choice, respect, expertise and risk management
 - There are too many service providers – There are closer to 160 service providers rather than the 257 contained in the report

Summary of Key Themes Arising from Written Submissions

Self-Advocates

What helps you to have a good life?

Written respondents said:

- Having a variety of things in my life
- Support in navigating the system
- Having family, friends and loved ones
- Having a relationship
- PDD giving agencies enough dollars to give me more services
- Me getting to choose the amount and kind of services I need
- Being included, valued and treated like I'm important
- More education
- Being treated with respect
- Everything in plain language
- Being able to go after my dreams
- My self-advocacy group
- Positive encouragement without criticism
- Being validated so that people believe me
- A strong relationship with my partner
- The right to know that no one has control over me
- Affordable and accessible housing
- Being able to keep my workers
- Learning to be as independent as I can be
- PDD supporting the "right to love"
- Grants for local groups to create arts, education and advocacy
- Supportive employment options

What doesn't help you to have a good life?

Written respondents said:

- Unqualified and uneducated staff
- Prejudice and discrimination based on our disability
- Exclusion and neglect

- My guardian – they have control over me
- Having staff change all the time
- Being called names
- Being on your own with no staff or roommate
- Having no safe places for us to be ourselves
- PDD not listening, some of us fall through the cracks due to funding
- People treating me like I'm a baby
- Not having more input on what I want from my life
- Can't get a mortgage or RRSP because I have a developmental disability
- People not understanding me

Measuring performance – do you feel comfortable talking to your service provider?

Written respondents said:

- Yes, but I do feel like I need more people to talk with
- No, they never listen
- I would feel comfortable talking to a service provider if I could get one
- Service providers make me fit their qualifications
- I'm forced to share supports with people who I don't have any similarities with
- Yes, staff meets with me every day. Sometimes they listen to me
- I'm worried there might be repercussions if I complain
- I'm uncomfortable talking with my service provider

What's one thing do you wish you could receive from your service provider?

Written respondents said:

- I wish all service providers put their clients first
- Help me make phone calls to help me be independent
- I want them to help me go to a college program
- Help me find friends, help me find a date
- Maintain my goals of being independent
- Help me learn about money and counting how much money I have
- Make sure that I am part of the decisions and conversations that are about me
- Support and respect my decision or choice, even if they don't agree