

STAYING TRUE TO THE VISION

A RESPONSE TO

***Transforming Community Living Services in BC
(Jan. 6th, 2005)***

Community Living Coalition

February 9, 2005

INTRODUCTION

This document is intended to provide both feedback, raise pertinent issues, and questions related to the proposed support model and organizational structure of CLBC as detailed in *Transforming Community Living Services in BC (January 6, 2005)*. Our intent is to continue the process of ensuring we have the best possible system for supporting individuals and families: a system which respects self-determination and choice, is flexible and responsive to individuals' and families' needs, and which enhances community capacity and integration that is fiscally sustainable and responsible.

We recognize that there may be areas where we do not have the full information available or areas where there is misunderstanding of the document's intent. Accordingly, we sincerely hope that this document serves as a basis for dialogue and is not seen as simply a critique. As the community body, which began this process in 2001, we are committed to ensuring its success and it is in this spirit that this document is written.

We begin with some background on the Community Living Coalition and how we developed this document and then address what we feel are the most critical issues and concerns. We conclude with a summary of key issues and concerns.

WHO IS THE COMMUNITY LIVING COALITION?

The Community Living Coalition [CLC] is an open and inclusive gathering of people and organizations dedicated to empowering individuals and families to make decisions about how they lead their lives in the community. To achieve this vision, the coalition has worked with the Ministry of Children and Family Development, the Interim Authority for Community Living, British Columbia, and the provincial government to develop a new governance structure for community living for children with special needs and adults with developmental disabilities. Individualized Funding (IF) is seen by the CLC as a key mechanism to ensure families and individuals exert decision-making control over the funding for their supports.

In August, 2001, approximately 50 people representing families, family groups, advocacy organizations and service providers met in an attempt to organize a response to the policy direction of the Ministry of Children and Family Development to move community living services for adults with developmental disabilities and services to children with special needs to a new community-based governance structure. Out of this meeting, the Individualized Funding Family Coalition was formed to organize a province-wide meeting of family leaders interested in working with government to develop a policy on IF as an **option** for families and to incorporate it within any new governance structure.

On September 22, 2001, over 75 community and family leaders from BC met in Vancouver to discuss how IF and a new model for community governance could be implemented provincially. Families shared stories about the empowering role of IF, and discussed the government's new interest in supporting both IF and a governance model that would move decision-making closer to the community.

On a parallel track, by early October, several groups had worked to respond to the MCFD restructuring proposals by submitting recommendations on new governance alternatives and other policy considerations. These included a group of nonprofit service provider associations under the name Vision for Community Living, the BC Association for Community Living (BCACL) and the Joint Committee of BCACL.

Ultimately, the various groups agreed to unite as a Community Living Coalition to present a strong, united voice to government. On November 1st 2001, the Coalition was created and began meeting on a regular basis. The Coalition worked closely with MCFD and actively participated in the Community Living Transition Steering Committee and the Interim Authority for Community Living, British Columbia to:

- address the cutbacks to community living services and supports;
- develop a new governance structure for community living;
- promote Individualized Funding as an option for individuals and families.

HOW THIS DOCUMENT WAS PREPARED

The CLC consulted its participant mailing list of over 900, seeking input on the *Transforming Community Living Services in BC* document. A few members of the CLC who were present at the January meeting agreed to prepare a response based upon member inputs. This report reflects those inputs and previously supported/principled positions taken by the CLC in the collaborative efforts to restructure services, governance and financing of community living. The response from community was very wide-ranging and clearly focused. We will try to reflect that commentary in its entirety and provide emphasis on matters that were either repeatedly stated or reflect the fundamental points of concern inherent in the initial vision or previously agreed negotiations with government. The timelines for response from the people and organizations on our mailing list were short. Despite this, we heard from a great many families, service providers, self advocates and MCFD staff. A sample of the responses can be found in appendix one.

CRITICAL ISSUES AND CONCERNS

Vision And Principles

We are very pleased to see the clear statement of commitment to the vision and principles, which have been developed over the past 4 years. It is this shared commitment, which will form the basis of moving forward in a constructive and productive manner.

We are, however, very concerned that the content, tone, language and proposed structure and associated job descriptions do not reflect these principles. For example, it is disturbing to see a caveat introduced immediately which suggests families are to be 'actively involved' but 'may not always be the final decision makers'. There is a rather glaring contradiction with the third and fourth principles. No one has ever suggested that individuals and families will be able to determine funding or access funds when the

budget is fully committed, but they will be the decision makers within the policy framework established by CLBC, whether that decision is to accept what is offered or to walk away, or to try to find another way to meet their or their family member's needs. Sadly this paternalistic, overly bureaucratic tone pervades the document, and more critically, the proposed model.

This is further reinforced by the organizational characteristics aligned with the principles on pages 5 & 6. The first phrase references: 'decision taken on behalf of individuals and families', a practice we had hoped the new model would end. The second principle does not reference community decision-making, nor is this reflected in the documentation. Sustainable supports make no reference to choice, independent planning, the flexible individual and family support policy [which the IACLBC board ratified in June, 2004] or individualized funding - all key elements required to implement these principles. Access to flexible and responsive supports again requires many of the mechanisms mentioned previously, but most critically, the process outlined does not appear to change the current model, which is far from flexible or responsive. The language of 'intake and assessment' replaces informing and supporting. The broad approval, monitoring and oversight powers of the Operations Analysts, coupled with the failure to denote a direct approval route for straightforward requests from individuals who do not require the support of a facilitator, suggests the key organizational elements required to meet the demands of this principle have been removed or severely compromised. We will return to many of these issues below.

The Role of the Planning Council

It is our assumption that this replaces the role of the Planning Support Commission. More detail is needed as to how this is intended to operate. The Commission was governed by bylaw #2, which when it was passed by the Interim Authority board, gave it certain powers to ensure planning support was carried out in an independent and effective manner and was not unduly compromised by pressure from the operations side of the organization, or the board itself; hence the requirement that a 2/3 majority of the board is required to change commissioners or the by-law. It is very unclear if these safeguards and authorities are still in place. The reason for the commission was to ensure **independent planning support** retained its integrity, rather than overseeing 'standards and guidelines' of 'individualized planning'.

The current MCFD model would claim to have practiced individualized planning according to standards and guidelines for many years, but the lack of independence has often made it ineffectual. MCFD has adhered to a planning process based on the use of Personal Service Plans that are inconsistent with accepted international best practice in person centered planning. Finally, a further role of the Commission is to foster other forms of planning support that are currently in place in many agencies to relieve the CLBC of some pressure on their facilitators: hence adding both efficiencies and choice to the system. This requires, however, a direct means of access to the Operations Analyst. Again we will discuss these issues further below.

The Community Service Councils

The original Community Service Council model envisioned a more robust role than just advising the centre manager. . It is a shared decision making role, which in some cases, those communities who wished to, could undertake control of certain aspects of community and service development. The previous IACLBC board in fact approved Bylaw #3 which was to enable local communities to negotiate a delegated governance role, or to exercise a key advisory role pursuant to an agreement with CLBC. Even in cases where this was not the preference of communities, they were seen as having a role in staff assessment and community development. The input on planning, indicated as a role for the CSC, would be more effective through the planning council.

It seems clear that that this robust role for community councils has been abandoned. This also has the effect of undermining the commitment to community level innovation and enterprise. History demonstrates clearly to us that community ideas and energy are required to challenge the fundamental conservatism of bureaucratic structures, regardless of how good or principled they are.

The Organizational Structure

The three key functional responsibilities noted on page 7 reflect, in our view, the change in tone from an empowering, supportive model to a highly traditional, paternalistic model. The language of service delivery and quality services itself contradicts the notion that the system's primary job is to support people to lead lives which are inclusive and self determined. Services may play some or even substantial roles in this process, but they are means to an end, not the end. The move to community governance was always driven by a desire to create a structure and policies that would support people to lead a good life – it was not focused on creating services. They are merely one form of support that people may or may not require. By focusing exclusively on service delivery it will continue to foster a resource led, dependency culture which will not only mitigate against self determination and innovation, but will ultimately hamper efforts to find efficiencies in the system and ensure maximum values for scarce funding dollars.

On page nine and elsewhere reference is made to monitoring the quality and effectiveness of services. We feel this needs to go further and the individuals and families need to be the key driver of this process. We would also add that measurement of outcomes was a recommendation of the ministerial review of the IACLBC model, and it was a recommendation, which was enthusiastically embraced both by the authority and by community. The model appears to move away from self reporting by individuals, families and providers, and places great power in the hands of OA's to hold people and provider's accountable. Holding the community accountable seems to show through in many places in the document rather than safeguards as ultimately being something that happens at the community level, which is where they must be to have an impact.

Provision of Quality Services and Community Planning and Development

We are extremely pleased that the document retains the commitment to a separation of planning support and operations. We are, however, concerned that the structure and roles do not really reflect the need for both a separation and a reasonable balance of power. While we recognize that the two 'arms' need to cooperate (as has been stated in all previous documents), and need to operate under a shared set of principles and within a shared policy framework, we feel the modifications to the model go further than what is required, and in essence, closes the two roles back together again at the ground level. The proposed model looks distinctly like a typical MCFD office is right now with people with various roles operating under one roof – the resulting community based case management model as we know has largely been rejected by the community, and was one of the primary drivers of the desire to move to community governance and create a new model. We are further concerned that the primary role of supporting individuals and families to make and act on decisions has been replaced by a more traditional approach of assessment and gate keeping. Below are some of our key concerns:

- The VP Quality Services: again, is a title which does not reflect the intent of the new model and reinforces a service led culture;
- On page 7 the term 'individual planning' has replaced 'independent planning support' and it is noted that 'individuals and families are to be actively involved in developing plans'. This reflects a fundamental shift away from the intention of the new model and does not reflect the principles noted. The role of the Facilitator is not to intake and assess people and develop static plans, but rather to support individuals and their networks to make and pursue their own life plans. The facilitators are there to support that process, not to simply act as a gatekeeper to services. Their role was also seen as dependent upon individuals and families deciding to use them, or not. As currently structured, the Facilitator will not have the confidence of individuals and families because they will be seen as having greater accountability to a system, rather than a partnership with individuals and families. The previous model supported by community was based on creating partnerships, while at the same time having Facilitators very clearly understand and work within the existing funding and policy framework. The revised model merely replicates the case management model while making a greater commitment to do individual planning better.
- **Operation Analyst Role**
 - The Operations Analyst role has apparently been broadened to include approval and oversight of plans. It is important to point out that a person's plan is their vision of a desirable future. No one else can approve or reject this. Rather, an analyst's role should be limited to approval for CLBC resources, which might be used to implement that plan. This is a major augmentation of the role, which was limited to assessing eligibility, and approving resource allocations based on clearly articulated policies. It was also recognized that this may involve approval pending availability of funds. Further it will inevitably lead to a replication of the current system where multiple levels and approvals will be required for individuals to get supports. Once again this reflects a service led approach. Finally it is difficult to see how the facilitators will not become subordinate in an environment where virtually all the work of the Facilitators must be approved by the OA.

- The monitoring role has also been expanded to cover all aspects of the plan rather than simply those involving resources and contract compliance. The facilitators are the appropriate vehicle for monitoring whether the supports are what the person wants and needs. The original model also called for a great deal of self-reporting, both by those using services, and those providing them. This accepted accountability and compliance mechanism seems to have now been lost, with a renewed focus on professional oversight and control. This is expensive and will do little to build needed partnerships with community. The individuals and families will ultimately monitor how and whether their wants and needs are being effectively addressed.
- There seems to be a great deal of confusion both in this report and in the Milowsky Report as to the role of the OA with regards to crisis response. This role was always envisioned as appropriately done by local networks of service providers, emergency response personnel and families. Indeed, the IACLBC has done a great deal of work on planning these networks. The OA's role is simply to ensure that an appropriate response system is in place in each community and ensure resources are available to respond effectively. Where necessary, the facilitator will be best placed to assist in the planning of a response with the individual and his network.
- This leads to concern around the location of the OA within the Community Living Centres. The Milowsky report raises concern about the location of the OA through a series of quotes Pages 6-7, many of these refer to the limited role noted above in crisis response and hence the issues are not as prevalent, nor as acute as the quotations out of context might lead one to believe. That said, the placement of OA closer to the CLC is not in itself a major change, housing them within the Centres, however, will create a significant additional pressure on the independence of the planning support. Coupled with the concerns on the role expansion noted above, this will further reduce the autonomy of the facilitators and will inevitably change the culture of the centres. A well noted axiom in the disability field is that disability policy is a function of fiscal availability – translated very simply, this means that the OA, who has considerable power in the proposed model, and who will focus on cost containment and accountability, will drive the culture. The commitment to community inclusion, choice, flexibility and innovation, which require the trust and engagement of community, will be subordinate to this fiscal commitment.
- The number of OAs is not specified. The Milowsky report calls for an increase based, in our view, on a mistaken understanding of the scope and role of the OA and Facilitators. In short, there are significantly more Facilitators, as they are the ones who need to be able to work intensively with individuals and families and in their communities, to identify supports and resources, set up individualized arrangements and address changing needs in a proactive manner. This is a far more time intensive role than the current MCFD Social worker role. The OAs, on the other hand, have a clearly prescribed role, as discussed above, which is in the main, is one of assessing eligibility against clear criteria, approving or denying funding requests, again against criteria clearly laid out, contract management and ensuring each community has an appropriate crisis response system.

- The error in both documents is envisaging a much-expanded OA role and direct involvement with individuals and families. In many regards, if the role is to be expanded in the manner described, and located on the ground, it becomes almost redundant to have the facilitators at all. It would be far more efficient to do away with the independent planning function and employ a lower grade social work assistant to do intake and assessments to pass on to the OA.
- The OA Manager as also the Community Living Centre manager seems inappropriate when the key function of the centres is to provide planning support. Centre management would more logically be part of the planning manager's role.
- On page 27, the Operation Managers job description does not include contract negotiation. It is our view that for the larger, ongoing contracts it would be more appropriate for the OA managers, rather than the line OA, to negotiate these contracts.
- A final point related to the OA function and the system concerns the capacity of individuals and families to deal directly with the OA if they do not feel they require planning support - for whatever reason; be it the simple nature of the request, the individual is receiving planning support elsewhere, or a simple preference to deal directly with the resource and eligibility decision maker. Clear and simple policies and forms available via the web, picked up at the centre or through service providers that can be forwarded directly to the OA, will eliminate much of the needless bureaucracy of the current system and create efficiencies in the system to free up resources for direct support.

- **The Facilitator Role**

- The role of the facilitator, while remaining largely intact from the previous model has some additional responsibilities that could compromise the original integrity of this position. Many of the concerns regarding a 'bureaucratization' of the role are discussed above. There seems to be some confusion in the document, with a more traditional role such as intake and assessment and 'offering a range of funding and service options': (page 28), being fused on. The role of the facilitator, as originally conceptualized, which is also consistent with international initiatives, is to support the individual and family, to help identify support required, and secure the means to pursue their life choices. Accessing CLBC funded resources is only part of their job. This is the critical aspect of the role if individuals and families are to be empowered to move beyond a purely service dependent lifestyle to full integration, and if CLBC is to realize the efficiencies inherent in such an approach.
- The document does not reference the mobility of the facilitator, particular in more remote areas. We are unsure whether a mobile work force is still part of the delivery plan.
- Supporting the development of personal networks where required, which would involve linkage to community bodies which can undertake this role, should be part of the job description.

- **The Community Living Centres**

The Community Living Centres were envisaged as open and welcoming places where families, self advocates and facilitators could meet when required. The IACLBC has developed draft architectural plans for at least two centres which model the nature of these as open shared space without staff having offices beyond temporary work and meeting rooms and space for administration. By grouping the financial and resource decision makers together with the facilitators it essentially replicates the current Ministry offices and will again lessen the degree to which they see the facilitators as independent planning supports and the centres as places where they can feel at ease and welcomed.

- **Budget Regionalization?**

The budget management system is not clear, however, at times it seems to suggest a return to regional budgets. While we agree that equity and fairness are critical, this is on an individual level. Equity and disaggregation of budgets is what is required to move to any Individualized model of support.

- **Innovation and Enterprise**

The innovation focus is very much downplayed in this model. It does appear in places; however, it is largely presented as a component of certain job descriptions. Previous research indicates that unless organizations have a specific cultural focus and resources committed to innovation it is much less likely to occur. We urge CLBC to ensure this is a robust element in the new model and to dedicate a separate work unit that can liaise with other CLBC work units, and the broader community. Innovation and enterprise do not result when conducted off the side of someone's desk.

- **Policy**

We do not see any reference to the "flexible individual and family support policy", or to a clear transparent policy focus. We recognize that this may be outside the scope of this document but urge CLBC to retain a commitment to an integrated policy framework. The previous policy direction adopted by the IACLBC was based on best practice, and the advice of highly respected international consultants who work with a variety of human services.

- **The Monitoring Role**

- The monitoring role for personal outcomes should philosophically be lodged closer to the facilitators and not with the OA's.
- The advocate for service quality office role should report directly to the Board of CLBC and the Minister.

- **The Corporate Services VP**

The second and third bullet of the job description regarding managing centre staff and budget seem to be confused with the VP quality services role. This role may be more appropriate as a Director rather than a VP, which could create unnecessary tension with the other VPs.

Individualized Funding

One of the cornerstones of the vision has been from the outset access to individualized funding as an option for individuals and families. Given its centrality to the vision we are very surprised to see no reference whatsoever to it in the document. This was raised by most of our respondents from all sectors of our community. Its absence is disturbing in light of the other omissions and reorientation of the model back towards a more traditional bureaucratic structure. We would like clarification on the board and Ministry's position on this central part of the transformation vision.

CONCLUDING SUMMARY

While we will not attempt to summarize the entire document, it is important to emphasize the following key concerns as discussed above:

- **Individuals and Families have gone from active decision makers to junior partners;**
- **Community has gone from partner/collaborator to passive observer/advisor;**
- **While maintaining a general separation of the Planning support and resource functions, the power balance and location has been shifted to make the facilitators role little more than intake and assessment and the resulting system functionally little different than the current model;**
- **'Independent Planning Support' has become individualized planning with a range of service option being on offer;**
- **The focus on a model of empowering people to control their own life and break their exclusive dependency on services has been replaced with a traditional bureaucratic model;**
- **Individualized Funding, a key element of the new vision, is completely absent;**
- **In light of the above it is difficult to see how the proposed model will realize either efficiency gains to enhance resources available for support or significant gains in quality of life for the individuals and families it serves.**

As noted in the introduction, our intent is not to criticize, but rather provide the basis for a meaningful dialogue on the future of community living-and more importantly, for the future of individuals and families which rely on the support of communities and government. We are encouraged by the shared vision and principles noted in the document and trust that these will form the basis of a shared commitment to a future where all British Columbians live a good life in our communities.

To Comment On This Document, Or Get More Information Contact:

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or

<http://www.communitylivingcoalition.bc.ca/>

APPENDIX

A SELECTION OF COMMENTS FROM COALITION MEMBERS AROUND THE PROVINCE

The subject line is deliberate putting MCFD before CLBC as the new model shows that CLBC is under the control of MCFD. That CLBC is not family, individual and community driven.

My concerns:

1. The lack of information coming from CLBC or MCFD on the progress of transformation. The actual facts, figures and plans. Example: there is no discussion in communities about Community Councils yet implementation is planned for this year. Are the people on the Councils volunteers, elected or appointed? The model talks about Councils liaising with individuals and families in communities. Two questions: What about confidentiality? Are the councils going to be made up of consumers or professionals?
2. No talk in the model about IF. One of the main pillars of the vision of transformation.
3. Information that comes out is not in plain language so families and individuals understand it.
4. Two managers in each community. This is not only not cost effective families, individuals and caregivers will be dealing with two managers rather than one. The model shows that the families, individuals and caregivers go through the facilitator well we all know with the case loads they are going to have that we will be bypassing them to get services and information. In the original discussions there was an avenue for families, individuals and caregivers that did not wish to use a facilitator. We know there are families that can do that and this was supposed to help with case load. Where is that in the model?
5. No information on the appeal process and just what does referral to other services mean? If you get through eligibility you still have to get the plan excepted. No different then before except it will take longer as you have to keep going back to facilitator and take one step at a time.
6. Facilitators job description no different then a Social Worker except there will be less of them and they are expected to spend more time with each consumer building plans. The Social Worker was never responsible for making the decisions on eligibly or whether a person was going to get funding. They took direction from the money people and said yes or no as they were told. Do not see any difference here.
7. CLBC a new layer of bureaucracy no different from what health did putting in Vancouver Island Regional Health Board. They are appointed, responsible to MCFD and not the consumer.

8. What I would like to see are flow charts of the envisioned model to make a comparison to what we have been given. (side by side)
9. The model shows CLBC organizational structure how about one with MCFD's organizational structure, before CLBC and now, so we can see for ourselves that forming CLBC has reduced the government bureaucracy?
10. CSSEA criteria for eligibility makes it impossible for small non-profits to participate increasing their costs and work load. Definitely did not help with more individual services. Where in this model is the avenue for families, individuals and caregivers to give input to these types of bureaucratic decisions?

Parent of an adult child
Volunteer of a service provider
Vancouver Island

- 1) I did not see any mention of individualized funding in this entire proposal. WHAT HAPPENED TO THAT???
- 2) This thing is full of job descriptions, etc. all in bureaucratic language. Trying to read it is difficult -- but it sure sounds like there will be MORE bureaucracy and I thought the point of the exercise was to have less bureaucracy.
- 3) What authority do the "planners" actually have? I can see the point of dividing planning and funding functions to get rid of conflict of interest, but what is the point of all that planning if planners do not have access to sufficient funding for individuals?
- 4) All those "flow charts" and tables are very difficult for the average reader like myself to understand -- but it certainly does not look like a simpler process than what is in place now.
- 5) I am very concerned that most of the emphasis seems to be on "accountability" which is all well and good in terms of individuals actually getting what the service providers say they are giving -- but it is hard not to see this word "accountability" as meaning "control over expenses" and I am gravely concerned that there will never be enough money in the "system" to meet people's needs, but the "blame" will be shifted onto this so-called "independent authority" and away from Government -- much like what has happened with the School Boards in our Province in recent years.

This document is NOT easy for the average person to understand and if you really want feedback from us at the "consumer" level, a plain-language version might be helpful. Probably Executive Directors and so forth can understand it well enough, but for most of us, I believe this document won't get many comments because people will feel that they simply do not understand it but it "must be okay" if the people they trust -- i.e. the Community Living Coalition -- have participated in drafting it. I believe this needs to be addressed.

Sincerely, Cathy Lafortune

Hello,

I have a 24-year old daughter with high needs. Waiting for residential funding since 1999. Having had high hopes for this new individual funding concept, with all the many hours of input, just to see that bureaucrats win again and take the pie. What can you tell me? When can parents get the help they need?

After so many years of trying to water down the main concepts of helping the individual and his/her family, I bet you have already full knowledge what the Bureaucrats pay, benefits and their "Rights" will be. Can you tell me, what my daughter will be entitled to receive?

Gudrun Cave
Nanaimo

I am writing to you as a service provider. My initial response in reading the report was one of exasperation and frustration. Our hope was a model that would be individual, family and community driven. Instead we have a model that is bureaucracy focused and supportive of maintaining the employees that are currently with Community Living Services. These are the same people that have made the lives of many families in our area a living hell over the past few years. One document that I read stated that 400 current Community Living employees would make the transition to CLBC. I suppose they will need these 400 people to help maintain the current level of paper shuffling and stacking that occurs. This is not what families need. They do not care about accountability to the government but they do need support for their families.

We live in an area that has been severely under serviced for almost as long as I can remember. Ten years ago this began to change. Changes are not always a good thing, and from that point on our services were decreased, under supported and under funded. Waitlist grew out of control, and still no one would address the concerns and crisis that were arising with the families in our community. Families were left to flail with crisis, children were hospitalized and yet others were sent out of our community because we did not have the services to support their needs and there was no crisis plan in place. The frightening thing is that we do have the capacity in our community to address all the issues, but the one thing that was lacking was the support of a Community Living Office who cared about our families needs. From this we have dealt with years of being told "no", the fact that there is no crisis plan, having to send young children out of our community and away from their families for short and long term care. No one should ever have to send their child away from home.

One of my concerns with the Transformation document is "The Principles". These sound great, but they are just words on paper. They mean nothing as they are principles that should already exist. In our communities families and individuals with disabilities do not feel safe and secure. They have the sense that there is no one out there who has any concern for their well being. There is no respect or trust, and even though many families are near crisis, there is no focus on planning to support these families. The Principles are only the beginning of the shallowness of this entire document.

Service providers and families have made great concessions over the past couple years to help balance budgets, increase capacity and support the fact that we need to have a slim and trim service that provides effective and efficient supports in the community. Why are we all making these sacrifices and in return we get back the same blundering bureaucratic mess from the same heartless people as we had in the past. Service delivery has become more about quantity and accountability, not quality of service. Supports and services to families that have worked well have been slashed to increase capacity with existing dollars. So now we have had to cut programs that are already under serviced to provide even less adequate amounts of service to families on wait lists just so someone can spend an afternoon patting themselves on the back for the great job they did in making these changes happen. These changes did not happen in a cooperative working relationship; they happened because we were threatened that all services would be cut if we did not comply. This is another great example of the trust and respect that does not exist. Service changes continue, and now we are not even trusted to deliver the services we are contracted to do. We must now change from a direct payment that offers stability to a small contractor to billing for services. If anything we have so little available that we always do more than we are contracted to do. This is because we believe in the people we support, and will not sit by to see people deal with their stress and crisis alone. Our hopes and dreams for the future where our families would have less stress, and could actually receive the services they need to keep their family healthy, happy and together in their own community are gone. If all else failed, families could look at Individualized Funding options, but they do not see to even be under consideration in this report. With this plan the future looks pretty grim.

Thank you for the opportunity to express my concerns and frustration.

Name Withheld by Request

The primary difference between the vision of 2001, when many of us saw a draft organizational structure of what is now known as CLBC, and the (lack of) vision presented in January of 2005, appears to be a win for a bureaucratic structure over one that allows for actual community development. It seems to have strayed far from the path of innovation, and replicates a failed and failing system that will eventually collapse as it too (along with services) is unsustainable. This underlying problem will transcend any effort to change the culture of an entire ministry migrating directly into CLBC. No one would have thought to incur a great deal of work to change a system that was not already dysfunctional. This characteristic can be demonstrated in any number of areas, all easily identified. One small example lies in the search for information management technology. Not only is the situation stagnant after over a decade of fruitless endeavours by the MCFD but after an apparent attempt to involve the community, we are now told that it will take a further 18 months to deploy any technology into the field. No business could survive for a month with this kind of approach, and after a decade of many millions of tax dollars expended, there remains no visible or tangible asset.

Although it is not part of the service delivery model, it is worth noting due to budget constraints if for no other reason, that the Ministry's approach of sending 2 FTE's to every office in order to capture information and enter it into a data system that is (we are told) very labour intensive, and which cannot "speak" to other MCFD technology systems. If Ministry staff have been unable to enter data since 1986, is it prudent to

attempt this by simply adding staff? It has been the Ministry's sole method of problem solving for so long, that continues unchallenged. But what is the cost of this approach, no matter how well-intentioned? Why does the Ministry continue to reject the offers of service providers to give them the data they need? What is lacking that precludes acceptance of an offer made by "partners"?

It is a fearful thing to think that this type of approach will be duplicated by CLBC. Will the government or the Ministry ever really forego the power and control that would allow the community to respond and develop? This refers not only to technology (systems that can actually communicate with each other and government) but also to the sustainable supports to those who live with disabilities, which will only be possible with strong community involvement.

A decade ago Doug Allen proposed a Ministry that could run very effectively on 250 FTEs. The draft organizational structure for CLBC (2001) suggested a provincial organization of 220 FTEs that would serve families and individuals well. Now there are 400 FTEs "needed". At the same time as funding for an additional 180 FTEs is apparently available, the Ministry claws back money from service providers, including benefits to staff who actually provide the supports needed. How do we answer those families and individuals who remain on wait lists year after year? How do we justify these priorities?

In 2001, only two positions reported directly to the CEO; in 2005, six positions report directly to the CEO. Regardless of job title or "rank", this appears to be a 300% increase. In 2005, a whole new level of management has been inserted which was not deemed necessary at all in 2001. The Ministry states that demographics suggest an increase of close to 4% annually in terms of services pressures. Given that the community has no further capacity to give back money or to increase service levels, what will CLBC do in order to "transform" the system? What about the Ministry's three year financial plan and its impact? If the government is eager to "devolve services" it is because of its fiscal agenda. Is CLBC unaware of this struggle? Surely not. Has the question been asked: what is the actual operating budget of CLBC as an organization separate to the budget for contracted services? If is essential that we have clean information on this, or embarking on this proposed model could lead to tragic consequences.

Treasury Board is willing to fund a grant of \$325,000 to do research around "cost effective" models. Hopefully this research will actually provide a clear picture of what most consumers (in any market place) already know: that quality is economy in the long run, and that duplication of effort makes for an inefficient business. It is in the context of "no loss of position" (in the 2005 model) that one must put the examination of any "cheaper" models of direct services.

The Community Coalition had a deal with this government and that deal is being broken. The government said they would help and encourage us to let the community develop the necessary resources in community, simply so that appropriate support services would be sustainable. What opportunities for true innovation remain in the bloated 2005 model? How will the community ever receive the investment it needs to develop a sustainable infrastructure? The needs of the Ministry appear to regularly supersede the needs of our most vulnerable citizens.

The notion that one could "form CLBC" inside the Ministry and then "pop it out into the community" while "changing it afterwards" is naive in the extreme. History is filled with examples of how this has not worked. It would be an overwhelming challenge for most people and most organizations, and presupposes both a level of awareness and a total commitment to participate in order for a cultural transformation ever to take place. Will the hiring of an "expert" in changing an organizational culture do the trick? Who will be responsible for the outcome of this endeavour? If the culture is not transformed, then what?

The Authority has stated that it will become accredited by the end of its first two years of operation. Only a very superficial understanding of accreditation would suggest such a bold statement. Family members state quite openly that no "satisfaction survey" would ever suggest that the current model of CLBC would receive consumer approval. This would likely be accurate from the perspective of other community stakeholders at well. There simply is no language in the current (2005) model which suggests an understanding of what truly is a community driven philosophy. Values and ethics must underpin the entire organizational structure and culture, not be the faint hope of a tonic injected after the fact.

At this juncture, to have any credibility, the organizational structure must show people with impeccable community experience and demonstrated leadership filling every management position. The essence contained in the 2001 statement that allowed then Minister Hogg to speak with passion must be rediscovered. Perhaps Minister Hagen, a principled man, can guide the Board into a reality where this is possible. Shakespeare said "it is a consummation devoutly to be wished". And so it is.

Jordan Thurston, Service Provider

Our daughter has cerebral palsy and gets individual funding through the CSIL Program, Ministry of Health. She has autonomy and a full life where she is included in community. She is very happy. Changes need to be made to the MCFD CL service model so all individuals with developmental disabilities have opportunities for autonomy/self determination and an inclusive community life like people who qualify for the CSIL program have.

It is that simple.

Everyday, our family is incredibly grateful that our daughter gets the correct kind of service and support.

Please make the changes. Do the right thing. People are worth it.

Janice, Robert and Melanie Maxwell

I have a concern about the approach that is being taken with accountability. The document talks a lot about accountability to the Ministry and the bureaucrats but makes very little reference to accountability to families and/or service users. Although there is some lip service to this issue, most of the accountability mechanisms described in the document are administrative and focused on relationships between bureaucrats and service providers. In addition, I disagree with the delegation of service monitoring to the Operations Analysts. The facilitators are the people who will have the most contact with the service user and the family and be most familiar with their goals and wishes. The facilitator is more appropriately placed to gather feedback from users and families about whether the service is meeting the original goals. Finally, in failing to mention Individualized Funding, the document ignores a very efficient accountability mechanism - if the service user/family doesn't like it, they'll take their money elsewhere!

I also think that the sections on strategic planning fail to give the community the role it would like to have in deciding how community living services should look in the future. The planning process should be driven by the community, not simply involve us.

Finally, the term "Operations Analysts" has to go. The term is horribly inaccessible and bureaucratic.

Thanks

Fiona Lewis
Friend of a person who receives MCFD services.
North Vancouver

Hello,

I have read the service model and I have been supportive of CLBC concept from beginning:

- 1) New model is more bureaucratic focused than I would have thought. The original concept was not so. The key, I suppose, to having two managers in a center is selection. There can be benefits to having two distinct roles. The contract manager process is an excellent tool for change, innovation, partnerships etc. in each community. The first few years of CLBC will be developmental and may benefit from two distinct managers. The paramount success will of course come from the people in the positions and not the positions.

Eddie Bartnick has highlighted this in his critiques. If the same people occupy the same positions, the culture will unlikely change. How did the service model change so? Will government let go of power and transfer to CLBC at a structural level?

- 2) Family input and participation of community must be the foundation of service delivery. Without this, little will change. Again, if the bureaucracy still exists in the end, the determining factor to success might just be to ensure the managers positions are filled with staff/individuals who are not bureaucratic by nature.(open to taking direction as opposed to giving it and able to give direction when necessary, trust, values etc)

- 3) The decrease in autonomy for planners is noticed in the model but again, selecting appropriate managers may reduce the lack of autonomy the model portrays. The best leaders/managers will create an atmosphere that will allow for independence and creativity.(Selection is the key to the success of the model)
- 4) No mention of individualized funding is noted. Why?

Thanks for the opportunity to provide feedback. The model shows a thought out process. It changed somewhat from the original design and appears more bureaucratic. I believe it is the people who are bureaucrats and not the positions and that the positions must be filled appropriately from the start date, to assist this necessary transformation. The challenge then becomes a labour relations issue for excluded positions. My thought is that communities and families deserve more right to how and who fills the positions, than the people currently in them? Further, the Director positions are integral to the success of the model and the people in it (trust, input, accountability, direct access etc.) A key component for the hiring body is that they are able to select managers who have a demonstrated ability to take direction from citizens and families and are able to put individual needs first.

Cliff Andrusko,
Social Worker
Community Living Services for Adults

Dear Committee Members,

It does not seem to me that this board is hearing anything parents are saying. It also seems as though someone has decided this is the way it will be from now on and we as family\advocates have no more say in how service will be delivered to our family member(s)?

Our family member(s) are vulnerable enough without stressed out parents, who are told by some Ministry staff if we are stressed out to put our family member in care. When do you stop? When do you listen? When do you realize that IF was in place from birth to death you would save millions of dollars on all the staff you put in place who make our life more difficult? It seems the only reason is to hire more bureaucrats to make money off our family members with disabilities. Is that the legacy that this board\Ministry wants to leave? Enough already!!!!

Questions:

1. When you say, "...families will always be actively involved in planning and decisions but they may not always be the final decision makers", what specifically do you mean?
2. Will not allowing CLBC to make decisions for my son result in no funding?
3. Is IF even an option? Will the money follow the PWD?

4. Why are so many people getting paid to watch so many other people? (see the structure) Is this money coming from the Budget for PWD in BC?
5. Why are there not more parents involved in this "new" structure? The simple structure recommended before this report would work, it would save money, it would make our lives easier, it had checks in place why was it changed?
6. The adults you are taking "care" of are our family members why are you presuming that you know what they need and we don't?
7. There are professionals who value the contributions and knowledge of families of PWD's. Where does this component exist in this plan? How long have they worked in the field? How many PWD have they known? Yes, it does matter! (how many VP's do you really need)?
8. How many of your new ministry staff will actually know the PWD and how well will they know them in order to make service decisions for them? Will they require more "professional" input before the service is approved? Where is the money coming from for all the consultants who these people hire when they don't know what decision to make for our family member(s)? I know this happens as I have been in this system for 16 years and will be spending the rest of my life in it to make sure my son gets the support he needs. How many of these people hired can say the same?

Comments\Recommendations:

I find some of this document to be very vague and open to interpretation by your staff in what kind of "power" they may have over our family member(s) and I think the document should include:

"Families\advocates who are active in the PWD's life and have the legal right to speak for their family member\friend will be the final decision maker in all programs for the person(s) they support and the funding for their family member(s)\friend will support their decision(s)".

If you are referring to PWD who have no family members\advocates in this document please clarify that.

If you are presuming that you can make decisions for PWD who have active family members\advocates who have advocated for their family member\friend from birth please clarify that.

In my opinion the money saved from some of these "layers" of people and the huge number of "hoops" (read meetings) we as family members\advocates of PWD will have to go to to get support from birth to death would pay for many services/programs our family members are not getting now.

In most cases our family member has been in this system since birth why are we having to go to all these people to get services?? What has been learned from all the money spent on MEETINGS? ("There is no money for service at this time, try again in a year")?

I think it is about time you have a board of family\advocates, with authority to act, as the final decision makers in all the disputes arising from any decision regarding services made by professionals and not supported by the family\advocate.

Although some PWD are non verbal most have some way to communicate they are not happy. I feel this board of parents should also review all cases each year to ensure non verbal people with disabilities are content with the service they are receiving. The Ministry can appoint these parents to enable them to meet and support these PWD who have no one other than the Ministry to speak for them.

I know many Ministry employees do care about PWD unfortunately some see it only as a job. All PWD deserve caring, committed support and the government should have a board that is autonomous in reporting on the service for our most vulnerable citizens.

The money should follow the PWD from birth to death. You will eliminate many meetings and save time, money and stress on the PWD, their family, and the Ministry. It should not be so complicated.

We know our family member(s), their needs, their strengths, their vulnerability, let us full fill our commitment to them and stop throwing up road blocks in our way! Remember we are committed for life!

I would appreciate answers to these questions and feedback on my comments and recommendations.

Calvin's - Mother and Advocate,
Cheryl Baker

I have read the 28-page document "Transforming Community Living Services in British Columbia" dated January 6, 2005. Comments:-

1. The service delivery proposed seems top-heavy, with many bureaucrats involved in an array of executive functions that don't necessarily transform directly to services.
2. Service plans have to go from the facilitator to operations analyst and back to facilitator, back and forth several times between these officers. How can this ensure timely delivery of services?
3. How many operations analysts are there? Presumably one for each of the Community Living Centres. There needs to be clear definition of how the OA in each Centre interfaces with the other "bureaucrats" and the facilitator, and the time element involved. The OA seems to have awesome responsibility (and responsibilities) and I am concerned that the requirement to go back and forth between the facilitator so frequently will cause a backlog of paperwork, because that's what this system of "delivery" amounts to, and hence delay in delivery of services.

4. There needs to be some clear delineation of expected time frames for service delivery. Speedy and efficient approval of individual service plans needs to be guaranteed for the "transformation" of service delivery to work.
5. I do not see a specific planning protocol for crisis intervention or other contingency for emergencies.
6. The report was vague in specifying from a family or self-advocate's position the availability of services. It said a facilitator helps to develop an individual service plan (with the help of an OA), but what exactly can be included in the plan? It would help to list all possible services, in a general sense if need be, so that families/individuals can formulate a plan before going to a facilitator, and save time. Shortening the processing time for service planning and development will make the bureaucrats more available to serve more people and improve efficiency. The time element is crucial.

Cathy Liddle (parent, North Vancouver).

Hello, Thank you for conducting this process. After reviewing the new service model for clbc I have the following concerns/questions:

- * Model is top heavy hierarchy. Recommend unilateral model to support family and individual input and decision making.
- * Facilitators duties are very limited compared to current social work role. Does less responsibility mean less money for position performed primarily by women? What are their intentions, wage roll back to support hierarchy with all the responsibilities?
- * How does monitoring contracts/resources from afar equate to safety for individuals? Many hands on tasks performed by social workers now administrative functions?
- * Where is the protection for consumers at the local level? Who do they report abuses to? Where will consumers requiring counselling, assistance with problem solving etc., etc., go for this support and who will they talk to? Many social workers currently fill this role particularly those who do not have access to counselling because The Interior Health Authority refuses referrals from our consumers with mental illness because they are developmentally delayed first-this is discrimination by the way. Will the consumers be required to contact Victoria or some crisis line?? What if the individual does not know how to use a telephone will they ask the person who is taking advantage of them to call? What about the individuals who require trusting someone before opening up to them or those who become weary of the phone voice. Who will ensure that licensed facilities report abuses because we know they don't all the time. These kinds of things can't be performed from head office.
- * I wonder how busy facilitator's will really be without access to individualized funding. Where will all the need for planning come from? If we unbundle services in Salmon Arm they will fall apart and others will suffer.
- * I don't understand how a top heavy bureacracy equates into more accountability-more red tape, more people to say no to consumers?
- * Where does Health Services for Community Living come in? If we are responsible for facilitating planning who will case manage, who gets these people involved?

Lynn Cvitko, MSW
 Children and Adult Community Living Services

Thank you for sharing the Coalition's concerns regarding the proposed CLBC Service Model, and thank you for your hard work in advocating for individualized funding on behalf of all individuals and their families.

As a service provider, we also share your concerns.

With due respect for all the hard work that many members of the community have put into this change I would like to offer the following comments:

It appears that this Service Model has moved away from the original purpose which was to provide individualized funding so that people would have the option of moving toward smaller, flexible (and cost effective services) - if that was their wish. It is also difficult to understand from this Service Model how the "end services" will be delivered to individuals and families and who will be responsible for delivering the services.

In addition, it is unclear how separate "new funding" will be identified for individualized funding in a time of cuts to services. This Service Model appears to focus on the "structure" of the organization, while losing its focus on individuals.

As an advocate for the people we support (and their families), we are particularly concerned with the Principle Statement:

"These remain the essential elements shaping CLBC, with the caveat that families will always be actively involved in planning and decisionsbut "they may not always be the final decision makers". There will continue to be constraints related to the capacity of the system to respond and the specific accountabilities of CLBC and its Board."

I hope you will find this feedback helpful and thank you for providing an opportunity for the public to comment on this important change.

Name withheld by request