

**DALHOUSIE FAMILY MEDICINE ADULT DEVELOPMENTAL DISABILITY CLINIC  
EVALUATION TOOL:  
A KNOWLEDGE TRANSLATION ASSESSMENT  
SUMMARY REPORT  
April, 2015**

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### **About the Researcher**

I am a qualitative researcher who has conducted research related to the fields of Disability Studies, Gerontology, Gender Studies, and Education. I have been part-time faculty in the Department of Women's Studies at Mount Saint Vincent since 2005, and was a researcher for the Nova Scotia Centre on Aging from 2005-2013. I am currently a doctoral student at the Mount. I am not associated with the Dalhousie Family Medicine Adults with Developmental Disabilities Clinic.

## INTRODUCTION

This report features feedback from family physicians and patient guardians/caregivers regarding the Dalhousie Family Medicine Adult Developmental Disabilities Clinic (DFMADDC) located in Spryfield, Nova Scotia. The goal of the Clinic is to advise and support referring family physicians and assist in developing educational programs. One of the support tools provided to family physicians whose patients access the Clinic is the DFMADDC evaluation report. The goal of this research project was to evaluate the report to determine its usefulness for family physicians and patient guardians/caregivers. Four family physicians with a patient who had accessed the Clinic's services, and five caregivers of patients who had accessed its services, participated in this research project.

### Recruitment

Physician participants were recruited voluntarily through the DFMADDC physician list. An information letter was sent via mail to all physicians who had a patient who had accessed the services at Clinic. Physicians interested in participating contacted the project manager. Prior to each interview<sup>1</sup>, the DFMADDC gave/sent the physician participant a sealed copy of the patient's report, which had been previously sent to her/him, to enable the physician to refer to it during the interview.

Patient guardian/care-giver participants were recruited voluntarily with support from the DFMADDC physicians. An information letter was mailed to the guardian/caregivers. The patient guardian/caregivers then contacted the project manager to volunteer to participate.

Four physicians were interviewed, three by telephone, and one in person. Five caregivers also provided feedback: three attended a focus group conducted at the Abbey Lane Memorial Hospital in Halifax, and two who were not able to attend the focus group, were interviewed, one in person<sup>2</sup> and the other by telephone. Data were collected over a period of three months, between December of 2014 and February of 2015. The following is a thematic summary of results and concluding analysis.

### Methodology

Semi-structured interviews and one focus group were used to explore the experiences of the family physician and guardian/caregiver participants. The interview and focus group questions were developed by the DFMADDC research team based on their knowledge and expertise as well as existing literature. The questions were designed to elicit participant experiences with the DFMADDC.

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<sup>1</sup> Originally, a focus group with physicians had been planned, but due to their varying time schedules and constraints, the research team opted to do one-on-one interviews.

<sup>2</sup> This interview actually included input from the participant's husband, as he joined the conversation.

Transcripts were coded thematically, using an iterative process of moving back and forth amongst transcripts, comparing and contrasting, as well as looking closely for incongruities<sup>3</sup>. The caregiver/guardian transcripts were analyzed first. In order to better capture the voices of the three caregivers who participated in the focus group, three separate narratives were identified and constructed. These three narratives were then analyzed together with the two caregiver interview transcripts. Transcripts were coded without the use of software. Physician interviews were likewise analyzed and coded thematically. Three initial codes of “preliminaries”, “evaluation process” and “evaluation report” were divided into codes such as “detailed physical exam”, “response to report”, and “recommendations”. After each set of data were analyzed, physician interviews were then compared with the caregiver/guardian narratives to determine 1) thematic commonalities, 2) incongruities, and 3) moments where caregiver themes and physician experiences intersected. Four other themes eventually emerged in the narratives that highlighted the overall challenges that guardian/caregivers experience in providing care to their adult children with developmental disabilities. These were included in order to help capture the flavour of their everyday lives.

## **A: PRELIMINARIES**

### **1. Access to DFMADDC**

One of the first issues to emerge was that not everyone who participated had been aware of the Clinic and its work. Physician 3 observed that she was not aware of the clinic until she happened to share a complex case with a colleague, Brian Hennen, and asked him how he might address the patient’s issues. He urged her to send her patient to the DFMADDC.

Two physicians and two caregivers indicated they did not know what to expect from the Clinic. Caregivers tended to draw upon their experiences with the IWK and/or COAST, expecting similar services. Caregiver 5 said that she didn't have "a whole lot of expectations. I didn't know really what we were going to get."

Physician 3's observations complemented this view: "The process [at the Clinic] wasn't known to me, so I was not able to support or advise my patient what to expect...the family didn't really understand what was going on when they went." This lack of clarity on the function and role of the DFMADDC was also evident in the comments of

#### **Recommendations:**

1. That caregivers receive a preliminary phone call and/or package that explains, "When you come to the Clinic, here's what you can expect."
2. "I would have liked to know how many people ahead of time you were going to see from the team [and] who the team was."
3. It is clear from the data that there currently is not an adequate strategy for informing community physicians about the program and what it can offer. However, while it may be a goal to develop such a strategy, the Clinic would need to develop the capacity to meet increased needs from the community than is currently available.
4. Since providers were unaware of the educational sessions that the Clinic had offered, it is recommended that these sessions be continued through various community initiatives.

Physician 4, who was not clear about the intent of the evaluation: "I mean, they just identify her things [symptoms], pull it out of a big manual and send it to me. Is that the intent?"

## **B. EVALUATION PROCESS**

Two major themes emerged in the participant comments about the evaluation process.

### **1. Detailed Physical Exam and History**

There were a number of allusions, in physician and caregiver comments, to the complexity of the patients and the extra time that was required – which family physicians rarely have - to address the patient's physical and psychological health. Physician 1 described the clinic evaluation as being "very effective due to the thorough going over that the patients get", and added, "it's very detailed". She had, in fact, recommended the Clinic to a "number of colleagues".

Physician 2 noted that "it was ... helpful to have someone review this *complicated* patient and give me reassurance that I wasn't totally on the wrong track with him. It was also reassuring, I believe if I remember correctly, that I called them with a question after and they were familiar with him and were able to answer it." She explained that the Clinic had recommended a dermatology consult for her patient, which she said was

..definitely something with this *complex* patient that I miss .... because we're always dealing with an acute issue, that day, so for them to be able to ... step back, and not deal with the, as I say, the fire that day, you know, putting out the fire, they could just look at the whole person and see something such as a dermatology consult was good. They also recommended a medication, this was probably something that I didn't see the trees for the forest, or vice versa, so it was helpful for them to point out, you know, have a specific recommendation.

She also appreciated the "in-depth history about...vocation and social history that sometimes, once someone's an established patient, can almost feel awkward to go back and ask about."

Physician 3 said the report was "very helpful". She also noted, though, that "there was an attempt to organize some of the other testing that was required, or follow through on the recommendations of the report, however, neither the DFMADDC nor myself was able to access those, so the recommendations were not able to be followed through in the way they were identified."

Physician 4 stated that he was "impressed" with the amount of detail in the physical exam:

There's a good history of [my patient] there, there's a physical, which is quite thorough. I don't know how they did this, because you know, this is the sort of a

kid that, you know, you wave your stethoscope and she screams and yells ....this is a pretty extensive physical.

He went on to read from the report: 'Demeanor, head and neck scar tissue observed, lots of plaque on her teeth'- that's, you know, that's a gift, that's hard to know, they have heart sounds on here, sometimes you don't get to listen to her chest...". He noted that he would never have an hour and a half to conduct such a thorough examination.

Caregivers also expressed an appreciation of the physical. Caregiver 4 noted that "the first half of the visit was basically clinical: They did a physical which I really appreciated." She described her daughter as a "complex little girl" with a range of issues, including FAS, seizures and developmental delay. Caregiver 5 also found the physical to be very helpful: "We actually discovered that my daughter had reflux, which I didn't know because I always put off stomach aches as being more or less behavioural. So that was good." This discovery led to a change in medication and improvement in her daughter's health.

## ***2. Initial Meeting and Discussion***

The second theme that emerged in relation to the evaluation process related to the caregivers' initial meeting and discussion with the Clinic team. Caregiver 1's son was in a supportive private school when they met with the Dalhousie team. She indicated that she knew his time at the school would soon end, and she had hoped that the Clinic visit would help determine next steps for him. She related that a doctor on the Clinic team had said they would contact the school and get back to her; however, she had not heard from the physician or anyone else on the team since this initial meeting.

Caregiver 2 found the initial meeting to be very gratifying. "We kind of walked away from that meeting going [sigh], somebody listened. They looked at [my son] as a person. And where was this years ago?"

Caregiver 4 and her husband, on the other hand, described their visit to the Clinic as "frustrating". They had already accessed services that the Clinic team recommended, such as COAST and Breakthrough. Their daughter had a particular behavioural issue they had hoped would be addressed at the Clinic. They said that while the team did engage in talk therapy with their daughter about this issue, they felt this was ineffective because, they explained that their daughter is "always very compliant with other adults" and that in the end, this behaviour had not changed. Caregiver 4 also felt that the Clinic team had looked at their daughter "in isolation", when it may have helped to explore family dynamics. She said that at the end of the Clinic appointment, the Clinic team "sort of said, 'Well, there's no other avenues.'" She contrasted this experience with her experience with the IWK: "When we'd go to the Developmental [Pediatrics] Clinic everything was super upbeat. There was always, 'We can do this as a team. We're going to get through this as a team.'" Her partner described the IWK experience as "warm - the atmosphere is one of concern for the entire family. He felt the visit to the DFMADDCC "was very clinical" and "narrowly focused".

Caregiver 5 had found "a lot" of the discussion with the Clinic team was helpful. However, she noted that the team suggested several resources, including HACL, that are not available outside HRM; since she and her daughter live in the Valley, these were inaccessible to them. In addition, she had already done a lot of searching and advocacy on her own, so was already aware of some of the resources the Clinic suggested.

## **C. EVALUATION REPORT**

Not all caregivers or physicians had received/seen the evaluation report. Of the five caregivers who participated, four said their physician had received the report, and of these, three had shared it. Only three of the four physician participants said they had received it.

### **1. Responses to the Report: Physicians**

Physician 4 had not received the report until the day of the interview, so had not had an opportunity apply it in patient care.

Physician 1 felt the evaluation report helped her to provide better overall care. She said the report "provides lots of good information and summarizes it", and that she "always reviews the entire report and recommendations with the patient and their caregivers and we have a chance to discuss them." She said having the report "improves patient care", that it is "comprehensive", and that "there are little things that I haven't done or thought of doing, that can be done in a better way or can be done at all, 'cause they might have been done before." She said it "focused me more on medical issues that are specifically related to folks with disabilities that I may not have been aware of before" and that it also "crystallizes the meds a bit better, so I'm better able to fine-tune the meds". For her, the evaluation report was about "preventive health care and med reviews".

Physician 2's patient was one of the first to be seen by the Clinic, and a report, as such, had not been generated. Instead, there was a clinic note included within all the other progress notes. She said the information she received as a result of her patient's visit to the Clinic "provided a lot of assurance and comfort that indeed, he was complex and I was doing the best I could, and sometimes that's actually all you need." The report did not cause Physician 2 to change how she provided primary care, but suggested it might be helpful "if there were specific resources or references that could be included as footnotes or appendices that the physician [could review] to learn more."

Physician 3's response focused on the outcomes of the report for her patient, and her comments were detailed. She noted that there were challenges involved in organizing the testing required for her patient as a result of the assessment, and that neither she nor the Clinic seemed to be able to access the recommended tests. In the end, she referred her patient for a psychiatric assessment, and through this assessment she was

able to access the testing recommended in the Clinic report, through Mental Health. She noted, however, that a final diagnosis of her patient was not made until two and a half years post Clinic assessment. As a result of this experience, she said there is a "gap between the initial assessment, the ability to get testing done, and coming up with a diagnosis, or a plan ... for further assessment."

Physician 3 indicated that the report, itself, had not provoked changes to primary care, but that it had entailed doing "an awful lot that might have been done through the assessment." She noted that changes to primary care that were eventually made were as a result of consultations with another health care provider versus the Clinic report.

### **Recommendations:**

1. That "there be a better liaison or understanding of the services that each of those departments can access, and make them available to others if that's needed."
2. That the assessment outline what the assessment involved (e.g., "physical exam, neurological exam, psychological evaluation, social skills development"), as well as the tools that were used to complete the evaluation.
3. That there be a "better follow-up on the results of [the assessment] with a diagnosis or a plan to reach a diagnosis."
4. That the Clinic coordinate with other resources and that the assessment process recognize "the complexity of the issues these people come with."
5. That a clear goal of the Clinic and its scope be stated in the initial referral acceptance and again in the final report.

## **2. Response to Report: Guardian/Caregivers**

Caregiver 1, whose son is autistic, had received a report which gave her direction on how to find a family physician. She had since found a family physician; however, she indicated that he was not comfortable providing care to her son. Instead, he kept referring her to the IWK.

Neither Caregiver 2 nor the group home where his son resided had received the report. He suggested that ideally, both his son's care provider and he should receive a copy of the report, because this would facilitate the yearly individual planning (IEP).

Caregiver 3 had seen the report but did not comment on it. Neither Caregiver 4 nor her physician had received the report.

Caregiver 5 "really appreciated having the lengthy report", noting that she put it away for future, "if needed, kind of thing". Caregiver 5 noted the report was useful in two ways. One, it provided a new diagnosis of acid reflux and a recommendation she be put on a medication for reflux. This new diagnosis also provided an opportunity to talk to her daughter about reducing her coffee consumption. Second, it gave a referral to COAST



to address her verbally abusive behaviour, resulting in a prescription for Risperdal, and also connected her daughter with Community Services to cover counselling sessions.<sup>4</sup>

**Recommendations:**

1. That the report be provided in electronic format to save physicians having to retype the information into the EMR (e.g., copy and paste).
2. That the report identify clearly, 'the following was done, whether it was physical exam, neurological exam, psychological evaluation, social skills development'.
3. That the report outline the tools used to do the evaluation, "and then a better follow-up on the results of that, with a diagnosis or a plan to reach a diagnosis."
4. That the report include specific resources or references that could be included as footnotes or appendices to which the physician could refer.
5. That a copy of the report be sent to guardian/caregivers, who then have the opportunity to share it with the patient's paid care providers, should they wish to do so, to facilitate a collaborative approach to individual care planning.

### **3. Resource Recommendation/Information**

Physicians appreciated the recommendations to resources and information contained in the report. Physician 1 "loved" them "because if I'm not familiar with the information in the recommendations, I can go look it up. I've gotten both the name of the guidelines and copies of the guidelines and I like getting both." She also said she used the recommendations to develop goals of care: "It falls under preventive care, to make sure I'm doing the correct preventive care."

Physician 2 related that the report she received had made a recommendation to an anger management/counselling group that was felt to be particularly suited for an adult with developmental disabilities. She noted that while she was aware of the group, she did not realize "they would be a particularly good group to refer someone to." She said that while the patient and family did not follow through with this recommendation, she "appreciated knowing that that was a good resource".

Physician 4 liked the recommendations because of the time that it saved: "I don't have to go look through a million pamphlets, so I can see the ones specific for [my patient] that they've identified."

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<sup>4</sup> While we see the value in the recommendation of directly sharing the report to the group home, privacy legislation may present that. Alternatively we would recommend that the guardian/caregiver/patient share the document if they wish.

Physician 4 suggested the Clinic do "pre-dental physicals and things like that cause they have an hour to sit and I don't." In requesting a referral, you could ask for areas that you wanted identified ....you make that happen by using a form, a referral form. He suggested a checklist of items that could be checked off for investigation by the Clinic team.

Neither Caregiver 2 nor the group home where his son resided had received the report so did not know what the recommendations had been. Caregiver 3 had seen the report but did not comment on it. Caregiver 4's physician did not receive the report, so no recommendations were made. Caregiver 5's physician received the report, but did not read it. She indicated the physician pulled out the file at the caregiver's request, and when he saw the "lengthy" report, said, "This is too long. I didn't read it. I don't have time for this." She indicated the physician did not read the recommendations. As a result of this experience, Caregiver 5 suggested the Clinic produce 2 reports – the long form and a 2-page abbreviated version.

#### **Recommendations:**

1. That the Clinic generate two reports: a detailed report that begins with recommendations in point form, and a condensed, two-page "lite" version, in recognition of family physician time constraints.
2. That there be an opportunity for the referring physicians to request certain areas to be covered for the assessment<sup>1</sup>

#### **4. Barriers to Using the Report: Added Work for Family Physicians**

Three physicians noted that one of the challenges that came with the introduction of the evaluation is that it required (unremunerated) additional work on their part. Physician 1 noted that the report entailed a "huge amount of time on my end", explaining: I read it, I summarize it, and then come up with a plan for the patient. Often, it takes me an hour just to do that, and then it takes me another hour with the patient, and that's just the amount of time I spend trying to get information put together.

When asked what could be done to ameliorate this issue, the physician responded: "That's an MSI issue. Obviously, it would be easier if I were being paid to do those things ... I'm only being paid for 15 minutes, yet it takes me 2 hours. But still, I want the evaluation and the information it provides, and I want it all at once, so it's worth the two hours I put in.

Physician 3 outlined the work entailed in trying to get the testing recommended by the Clinic assessment, and work toward a diagnosis and plan of care. She said, "I had to do an awful lot more work that might have been done through the assessment." Caregiver 5 found her family physician's response to the report "very disappointing". When she mentioned it to him, once he located it, in his files, he said, "This is too

long. I didn't read it. I don't have time for this." He then asked her if there was "anything in particular he needed to do, you know, whether it was some blood tests or I forget what, so I mentioned that. So he did it." In addition, he did not review the report with her, which she had been told by the Clinic he was supposed to do.

### **5. Update Letters for Changes in Care for Specific Syndromes**

Physician 1 said she would like to receive update letters "cause otherwise, I might not know." She added, "So if they would pass along to me any new guidelines, or even just a link to get to the information, that would be great". Physician 2 advised that she did not need update letters because her patient – who is an older adult - did not have a specific syndrome. Physician 3 advised that update letters would be helpful, if the information was "very specific and very individual".

### **6. Tools for Primary Care of People with Developmental Disabilities**

Physicians 1 and 4 were not aware of this resource. Physician 1 noted, "See that's the challenge, I don't know what I don't know. So if there's resources out there I don't know about, then I don't know to seek them." Both Physicians 2 and 3 had heard of the Tools, but Physician 3 never used it because she didn't have the time to print it off. She said if she received a hard copy by mail, she would put it on her desk and use it. Physician 2 said she didn't use the Tool because she didn't have any patients with a known, identified, syndrome.

## **D. OTHER COMMON THEMES...**

### **1. "Ageing Out" of the IWK: A "Scary" Transition**

A central theme running through caregiver comments related to the challenges they and their families faced as their children became adults and "aged out" of the IWK. Caregivers indicated that while their children were receiving care through the IWK, they felt connected to a supportive team and the necessary resources. Caregiver 2 observed:

At the IWK, they are a child ... and everybody is looking out for them. And then they're no longer children, and they're no longer cute little children, and they're expected to go into adult services, it's like wow, now where do we go? What do we do?

Caregiver 3's comments were similar:

As the magic age of 19 rolled around, I mean there's a real sense of being dumped, loneliness, anger, frustration, fear. When the phone rings and it's a care provider, I'm thinking I wonder if they've got a budget cut, you know.

For Caregiver 5, transitioning out of the IWK was “a hugely scary issue for me in many ways ... it used to be that I just saw a black hole for her after high school as far as what happens next, what does she do?” Caregiver 1 shared, “The IWK is the end. By the end, we go where? We don't know. There's no future.”

The transition from childhood to adulthood precipitated an intensive search for knowledge, resources and services, for caregivers, family physicians, and staff at the IWK. In fact, Caregiver 4 had suggested she take her daughter to the DFMADDC.

## **2. Need for Knowledge of Available Resources**

Over and over again, physicians spoke of the need for information and resources. Physician 1 said, “The challenge is, I don't know what I don't know. So if there's resources out there, I don't know about, then I don't seek them.” Physician 3 concurred, “What we don't know – we, meaning family doctors – is what resources are available [to our patients] out there. We don't know at all.” Physician 4 spoke of needing a sub-specialty list related to the needs of his patients with developmental disabilities: “I would like the specialist who's good for constipation in handicapped adults, the specialist who is good to do ENT exams -like a sub specialty list.”

Caregivers also spoke often of not knowing where to find the information and resources they needed. Caregiver 5, for instance, highlighted the lack of resources outside HRM. She said that “nobody tells you what services are available. This is one reason why the Dal [Clinic] is so important.”<sup>5</sup>

Caregivers 2 and 3 spoke of the need to educate parents of children with developmental disabilities when their children are young, about the importance of planning for the future.

...it might be helpful for people to have someone who can sit down and say, “Hey, you know, like Michael is cute now. He's 5 years old. But maybe you might want to start thinking now about when you're 50, you know.” And that gives the family some sort of opportunity to look at, well, what are we going to do? (Caregiver 3)

### **Recommendation:**

That resources be highlighted at the bottom of the report and a copy given to the caregiver/guardian/patient.

## **3. Caregiver Advocacy, Work, and Management of Care**

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<sup>5</sup> The “Dal team” had told her about COAST.

Given the ongoing need to find services and resources for their adult children, especially after leaving the IWK, it is not surprising that guardian/caregivers typically assumed the responsibility for advocating for their child and seeking the health and social services, and resources, to support him/her. Caregiver 2 gave an account of the daily kinds of work involved in his son's care:

You know your child. And you'd have to look at your child and figure out what was going to work for them. And you do activities, and...if the bowels weren't working, okay, well, let's get out for a walk and get things moving. And then you'd be questioning, okay, well, I don't want to give him laxatives all the time, Senokot cramps their bellies, and so what can we use that's a little more natural? So your brain is constantly going ... it's a full time job trying to figure out what your child needs. I mean the doctor, you take them and they'll give them medicine. And medicine is sometimes the answer, sometimes not.

Caregiver 5 said she was "a huge advocate and I'm not afraid to ... I go out there and I don't shut up ... so I get my daughter what she needs one way or another, even if it kills me." Some of this advocacy involved trying to find a family physician and/or specialists who would be willing to take into their practice an adult with developmental disabilities. Caregiver 2 said that as his son reached 19, the staff at the IWK "had to find a doctor who was willing to take somebody with special needs, because I guess a lot of them weren't. So we had to find somebody who was willing to take him."

#### **4. Expenses Borne by Families**

It was evident in the comments of several caregivers that they paid a lot of out-of-pocket expenses related to their child's physical and psychosocial needs. Caregiver 1, for instance, spoke of paying for her son to attend a private school, for his speech therapy (\$120 an hour), for supported swimming lessons, and other programs. A stay-at-home mother nearing retirement, she wondered how much longer she could pay for the services and resources her son needed. "I need to pay for these, [but] how to pay? Because I need to retire. And the family needs [someone] to follow this schedule." She had stayed at home to care for her son and "follow his schedule", so did not have paid work. She wondered, however, "how many years I can do [this]?"

Caregiver 3 observed, "There's a huge cost to families, and time. I mean, you don't live a life that's normal." Living outside HRM added travel costs to an already strained budget. Caregiver 5 spoke of travelling from the Valley to Halifax on a regular basis to access services and information related to her child's psycho-social needs. Caregiver 2, whose son was in a group home, shared his concerns: "I cannot say the number of times when the phone rings and it's the care provider, I'm thinking I wonder if they've got a budget cut, you know, and there's no money for this program or there's no money for that."

It should be noted that due to challenges related to the socioeconomic status of the patient, and/or limited system resources, recommendations may not be implemented.

## **E. SUMMARY OF FINDINGS**

Physicians and caregivers who participated in this research see value in the work of the DFMADDC evaluation and feel the services of the Clinic should continue. Caregiver 5 felt it is “a great service”, one that “probably needs some fine-tuning, like everything does.” Physician 3 said the DFMADDC is an “essential service”, one that needs to be “well-coordinated with other resources and recognize the complexity of the issues these people come with.” Participants shared the strengths of both the evaluation process and the report, and ways in which both could be improved. The following is a synopsis.

### **1. Strengths of the Evaluation Process**

#### *Detailed Physical Exam and Social/Vocational History*

Both physicians and caregivers valued the comprehensive physical exam given to patients by the Clinic team. Given the range of issues they and their families experience, their complexity, and the time constraints experienced by family physicians, it was difficult to conduct a thorough physical. Physicians said it provided in-depth information – social and vocational, as well as physical - about their patient, and was therefore extremely helpful.

#### *Information and Referral*

Caregivers valued meeting with the Clinic team because of the information they gained regarding resources, services and programs that may address the health and psychosocial needs of their adult children.

### **2. Improvements to the Evaluation Process**

#### *Inform Caregivers/Patients and Family Physicians about the Clinic Evaluation*

1. The data indicate that there is not an adequate strategy for informing community physicians about the program and what it can offer. It was felt that the evaluation process would be more fruitful if a) caregivers knew in advance what to expect going into the Clinic assessment – what would be done, by whom and why; this knowledge may enable them contribute more fully during the process; and b) family physicians were apprised of the role and function of the Clinic so they, in turn, can advise caregivers and patients. However, while it may be a goal to develop such a strategy, the Clinic would need to develop the capacity to meet increased needs from the community than is currently available.
2. Since providers were unaware of the educational sessions that the Clinic had offered, it is recommended that these sessions be continued through various community initiatives.

#### *Opportunity for Family Physicians to Make Specific Referral Requests*

It was suggested that referring family physicians have an opportunity to request certain areas to be covered for the assessment.<sup>1</sup> This would provide the Clinic with valuable information from the family physician, and ensure issues needing investigation will be assessed.

*Include the Broader Context (e.g., Family Dynamics) in Evaluation Process*

It was suggested that the evaluation should take into account the patient's living context (e.g., family dynamics) in understanding a patient's challenges; that a proper assessment of the patient could not be done in isolation. In addition, where the patient lives in relation to services and programs affects access (e.g., in HRM or rural?).

### **3. Strengths of the Evaluation Report**

The comments of physicians and caregivers indicate that the report is helpful in five key ways.

1. The guideline/recommendations are a valuable resource to both physicians and caregivers because they are so comprehensive and detailed.
2. The review of medications included in the report supports “fine-tuning” of medications.
3. It supports preventive health care.
4. It provides an opportunity to discuss patient progress with both patient and caregiver.
5. It can provide reassurance/affirmation to family physician regarding treatment of the patient.

### **4. Improvements to the Evaluation Report**

Participants made the following suggestions for improvement:

1. Ensure both caregiver/care provider and family physician receive a copy of the report so they can collaborate on individual care planning.<sup>6</sup>
2. Make the report more user-friendly for time-crunched family physicians by providing an abbreviated, short form report (e.g., 2 pages with recommendations) as well as the detailed report. This may increase likelihood that the physician reads the report, and shares it with the guardian/caregiver.
3. Include in the report an outline of what the Clinic evaluation involved (e.g., physical exam, neurological exam, psychological evaluation), as well as the tools that were used to complete the evaluation.
4. That a clear goal of the Clinic and its scope be stated in the initial referral acceptance and again in the final report.

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<sup>6</sup> Given confidentiality requirements, this is not permissible. However, the guardian/caregiver has the option to share the report with the patient's paid care provider.

5. That resources be highlighted at the bottom of the report and a copy given to the caregiver/guardian/patient.
6. Follow-up on the results of the evaluation with a diagnosis or a plan to reach a diagnosis.
7. That the Clinic coordinate with other resources.
8. That resources be highlighted at the bottom of the report and a copy given to the caregiver/guardian/patient.<sup>7</sup>

It should be noted that due to challenges related to the socioeconomic status of the patient, and/or limited system resources, recommendations made in an evaluation report may not be implemented.

## **F. LIMITATIONS OF THE STUDY**

There are three central limitations to this research study.

- 1) Despite many efforts on behalf of the research team, there was a low number of participants, and this prevents generalizability.
- 2) Interviews with the four physicians were brief due to their time constraints, averaging between 15-20 minutes.
- 3) Participants had accessed Clinic services at various points in time (e.g., one patient was evaluated before the Clinic began completing and sending detailed reports), so their experiences vary.

Despite these limitations, some common messages emerged from both family physicians and caregivers. In particular, there is consensus amongst the caregivers and the physicians who participated in this study that:

- 1) There is a need for enhanced access to information, services and resources in order to better meet the health and psychosocial needs of adult patients with developmental disabilities,
- 2) The Clinic is working to addressing this need, and,
- 3) With a little "tweaking", it could be an even better resource.

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<sup>7</sup> This recommendation was made by a Clinic team member.