

# PRINCE EDWARD ISLAND LEGISLATIVE ASSEMBLY



Speaker: Hon. Kathleen M. Casey

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## Standing Committee on Social Development

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LOCATION: POPE ROOM, COLES BUILDING, CHARLOTTETOWN

SUBJECT: PRESENTATIONS ON SUPPORT AND SERVICES FOR PEOPLE WITH DISABILITIES

**COMMITTEE:**

Janice Sherry, MLA Summerside-Wilmot (Chair)  
Jim Bagnall, MLA Montague-Kilmuir  
Paula Biggar, MLA Tyne Valley-Linkletter  
Michael Currie, MLA Georgetown-St. Peters  
Cynthia Dunsford, MLA Stratford-Kinlock  
Sonny Gallant, MLA Evangeline-Miscouche  
Robert Henderson, MLA O'Leary-Inverness  
Pat Murphy, MLA Alberton-Roseville, replaces Neil LeClair, Minister of Agriculture

**COMMITTEE MEMBERS ABSENT:**

Neil LeClair, Minister of Agriculture

**GUESTS:**

Community Inclusions (Ethel Ellsworth, Anne Mary Perry, Kevin Porter); PEI Association for Community Living (Bridget Cairns); Mabel Thompson

**STAFF:**

Melissa Keefe, Committee Clerk  
Ryan Conway, Research Officer

The Committee met at 1:30 p.m.

**Chair (Sherry):** Okay, everybody supposed to be here is here. So I guess we should get the meeting underway.

Welcome, everyone, to our Standing Committee on Social Development. I think the first thing I have to do is adopt the agenda.

**Mr. Bagnall:** So moved.

**Chair:** Okay. Today we have a couple of presenters. The first group being Community Inclusions are here to do a presentation, so we ask that 20 minutes to half an hour is usually a good length of time. If people have questions, I would appreciate if we would let everyone do their presentation first and hold your questions till the end.

Without any further ado, I will ask the presenters to introduce themselves so everybody knows who everybody else is.

**Kevin Porter:** Okay, I met a few people in here, most people. My name is Kevin Porter and I'm the executive director of Community Inclusions.

**Ethel Ellsworth:** My name is Ethel Ellsworth. I'm a residential coordinator with Community Inclusions.

**Ann Mary Perry:** My name is Ann Mary Perry. I live at the group home.

**Chair:** Okay.

**Kevin Porter:** We'll try to keep in time. I think we're probably going to come in at closer to a half an hour than 20 minutes, maybe even a little beyond that, but we'll keep that in mind, for sure.

**Chair:** Okay, that's great.

**Kevin Porter:** Great. Good afternoon to both members of the Social Development committee, ladies and gentlemen, and members of the press that are here with us today.

As I mentioned, my name is Kevin Porter. I'm the executive director of Community Inclusions. With me, again, is Ethel Ellsworth, residential coordinator, and Ann Mary, who lives at the group home in Tignish, and is a resident of ours. Note as well, Ethel is also the site manager of the group home.

First of all, I want to thank you for allowing this organization to present to you on a few goings-on regarding Community Inclusions, and in particular, some of the difficulties we have faced and are currently facing regarding housing. That's going to be the bulk of our presentation, but before we get right into that, and with the recent survey that we did three-quarters of the way through last year, I just want to talk a little bit about Community Inclusions itself.

Community Inclusions provides supports and services to adults with intellectual disabilities in the western PEI region. Basically, the north and the North Cape areas are clients that we serve. We do have people that participate in our services from all those geographic areas, from into the community centres right to the outlying areas of the region.

The supports and services that we provide, I'll get into those in a little bit with our website. It's something that we're really proud of. We had it developed last year. It went live actually on December 3<sup>rd</sup>, International Day for Persons with Disabilities, and I'll get into that, just to talk a little bit about our services. We're going to play a little DVD for you after Ethel's presentation.

Community Inclusions has been in existence

since April of 1998. It was the result of amalgamation of three organizations at that time: the West Prince Residential Services, the Tignish Normalization Workshop, and Maple House, Inc. Of note, all those organizations had a board governing their day-to-day operations. After amalgamation, Community Inclusions Ltd. was born and as a result had, and currently has, one board. There are nine members on the board covering the areas from St. Lawrence to Grand River and all from various professional backgrounds.

I should also make note, too, I said Community Inclusions has been in existence since 1998. Those services that I had mentioned, they were around - you're looking at the late 1960s, early 1970s, when services for people with intellectual disabilities - and even before that when there was things going on. So there's been a lot of going on with regards to services and the evolution of them.

Right now, I'd like to get into our website and I'll ask you to - the monitor - this is our website that we had developed by a private entrepreneur in West Prince, Innovative Tech Solutions. As I mentioned, we launched it live on December the 3<sup>rd</sup>. This is our home page here and there's a number of links. I won't go through them all. I know we're under time restriction: About Us, Residential Services, Vocational Services, the Employment Unit, Resources, Contact Us and our Home Page.

One thing I want to make note of it that's really neat, though, that I like is that when you go into web sites, you like to have a mix of pictures and wording and stuff like that, but it's nice when they're dynamic as well.

On the right-hand side - sorry, on the left-hand side - you'll see a What's New and Testimonials. The What's New could be our newsletter, it could be events going on, those kinds of things. The Testimonials,

every time you go in that picture changes. There's actually a client of ours that works for Ralph Craig at Craig Construction, just a little testimonial about how he made out on our employment program. You go back in, maybe there's an employer. So it's a dynamic thing. Sometimes you go into a website, it's static. The idea is you want to have people go in and hopefully get something out of your website.

The goal of Community Inclusions Ltd. is to ensure that every individual has the opportunity to participate in the activities and strong community life of West Prince.

Go into the About Us page - it's not me, it's your government server here; if I was in West Prince, this would be just flying - no, actually. No, it's not coming up for some reason. If it doesn't come up, I'm just going to -

**An Hon. Member:** Technical glitch?

**Kevin Porter:** No, it's not a type of glitch. Let's try Vocational Services. I'll get into the other one after. We operate two vocational workshops where, again, adults with intellectual disabilities, participants, come to our sites for various activities that we have going on.

The Tignish Workshop at the top there, it's more of a community-based workshop, but there's also lots of things going on at the site. We have people working in the community. There's a lady that works at M J's Bakery three days a week. We have people taking part in school lunch programs. There's a lot of integration in the community. We also do social rec things in the community, outings, those kinds of things.

On site, you know, it's a working program. People help bake. They clean. They maintain the area. We also do life skills there. There's some social rec that happens.

We have a physical activity program which is very important for our clients. We do that as well. So that's one of our vocational day programs, and that's right in the Tignish area.

The Maple House Centre is similar but we have a fully functional bakery there. We have a storefront and we also have a - we do wholesale to the Co-op and to Guardian Drugs in O'Leary. So that keeps us quite busy. We've been doing very well. Anything that we're involved in, it's all client-driven. People think of Maple House as a business and it is in a sense that we want to run it as such, but if it doesn't assist our clients towards inclusion and toward their goals, it's not worth doing. So that's something that - it's a balancing act that we play there.

We also do furniture stripping there. You see a gentleman that's stripping down a chair. We don't do the refinishing, but the customer brings it in, we strip it down, again with staff support when needed, and get it back out to the customer. You'll see right here, we had a gardening technician a couple of years ago. This is that Farm Day down in Arlington Orchard. You have a client picking apples. This guy is quite an artist, Cameron Easter. There's our Maple House in O'Leary and a client, Lori Bridges. She's just doing some cleaning at our bakery. So again, we have the two vocational programs.

You'll see Residential Services. I'll let Ethel get into that after. She can talk a little bit more about what we do in our residence and also in the community.

Our Employment Program - server not found. Let's try you again. All right, we won't worry about you. Our employment program is funded through Service Canada and there's also some provincial money there through the local Labour Market Development Agreement, I believe, through

the Employment Assistance Services. We service both clients that are on site at our vocational day program and also clients that are in the community. There was a need for that program back - it stopped back in the late to mid-1990s. The late Sherry McInnis used to run Employment Options. We saw there was a need. We put a proposal in. We got funding in 2002 and we've had funding ever since.

We've had more people working in the community then we have ever had before. That just does not happen, especially - our clients need support, they're very capable, if you match what they can do with what the employer's needs are. That takes time, but if there's time allowed, it can happen, as it should happen. We should live in inclusive communities. The people should be given the opportunities to participate in their community. So we've been quite successful with that and we're quite proud of that. We have to apply for funding every year. I wish it was three-year funding but it is what it is and we'll live with it.

Okay, server is not found. Ethel, we're not going to be able to highlight your area. That's okay, we won't worry about you. You'll do fine. We won't worry about this, I mean.

**Ethel Ellsworth:** I'll just have to talk (Indistinct).

**Kevin Porter:** So there's a few other links there. In Resources, there's a whole bunch of different links. You guys are in there, the Association for Community Living, Community Connections, the Ministerial Advisory Committee for Disabilities is in there. There's a whole bunch of different things. Then: Contact Us. If anybody has any questions, they can send things to us and we can do our best to answer them.

This is just one part of our business. We're not selling widgets here. We don't expect

10,000 hits, but it's just a nice complement. We kept it fairly low cost. It's great for things like this because especially with inclusion, promotion, promotion, promotion. As far as what the issues are, what people are capable of, all those things, I can't say it enough. If I brought our media binder to you guys today, it's thick. We believe strongly in that. I think we do it better than anybody on the Island, to be honest with you, and we're quite proud of it. So this is just another component: talking to you guys, getting out to community meetings, press releases, word of mouth, all those things, but we feel very strongly about that.

So that's a little bit of information about Community Inclusions. Again, we're one of many NGOs on the Island, funded mainly through government. The furniture stripping, the bakery, the lunch programs, those all generate revenue. So that brings some revenue in, so it's not 100% government-funded. It's nearly that, but we also do some things that generate some revenue as well.

Okay, are there any questions thus far?

**Ms. Biggar:** First of all, I certainly am very in tune with what you folks have been doing over the last few years, having been involved up there. Do you have a ballpark figure of the number of clients served like on site and off site?

**Kevin Porter:** Yeah, you'd be hovering probably around 50, give or take. If we have somebody in the employment program, for example, or even somebody in a community living situation, we monitor both of those but the employment one - it's often been said that the goal of our organization is to work ourselves out of a job. If the client no longer needs support, the employer is fine, the client is fine, then we take ourselves out of the picture. Then we have new people coming in. So it does fluctuate.

But that would be a good number for you, around 50 individuals, that's both off site, on site, in our ALP program - which is our housing program and at our residence at our Group Home. Now that's not everybody. I don't know the particular statistics. I think there might be provincial ones, but as far as region by region, I'm not quite sure.

We don't service everybody. We're always finding people that, for whatever reason, they don't come, they're not aware of it. That's like anything else. Even with all the promotion I said that we do, there are still individuals out there that we are yet to serve.

We sit on the transitional unit at the high school, which is very important. For people that are coming out of school, people need some - whether they're going to school, to work, what have you. In Hernewood and in Westisle there's well over a dozen people that are going to be coming our way. Now, whether they all take part in the service I don't know, but at least we're there and promoting that we can be of assistance to you if you so choose to be a part of our program. So we certainly try our best to meet any of the gaps that are out there. There's always gaps, but I think we're doing a better job now with the employment program and other things than maybe we were previously.

**Ms. Biggar:** Just another follow-up question. In regard to addressing needs as they come up, do you evaluate your programs on a regular basis as to the need to add something?

**Kevin Porter:** I think so. I think probably getting more formally than it was. I'll hand it to the province in a sense that - and I'll talk about this after Ethel's presentation, I have a few things to wrap up with - they initiated some discussions with the various NGOs. One of those things, especially as it related to long-term planning, was

accountability.

In that accountability - and that's something that if we're getting funded by you folks and by the taxpayers of this Island, we should be accountable. We don't have a problem with that. So I think you're going to see a more formalized evaluation program. They want to look at case plans: How many people are you servicing, what are you doing with them? We have case plans for everybody that are updated on a yearly basis that we involve parents or caregivers. We do that anyway so we don't have a problem with that. We support it. So we're getting there. It's not perfect, mind you, there's always room for improvement, but it's pretty good.

**Ms. Biggar:** You have to be flexible as well.

**Kevin Porter:** No question, yeah. We exist for people that we support and not the other way around, yeah.

**Ms. Biggar:** Thank you.

**Kevin Porter:** I can answer if there's anything later on. If not, I'll pass it over to Ethel.

Thank you.

**Ethel Ellsworth:** Okay, thank you, Kevin. First of all, I want to highlight Community Inclusion's residential services and what we offer.

Community Inclusions, of course, operates a group home in Tignish where we provide services and supports to four individuals who live there on a permanent basis and they require 24-hour supervision and care. We also provide respite care. Now respite care is for when an individual comes and stays with us for a period of time. It gives families a rest, and it gives individuals a change in their lifestyle. We also have emergency respite care where if there's a

crisis in a family in a community, well, they know at any given time, day or night, we have a place for them to stay. So we provide that at the group home in Tignish.

Our respite, over the past fiscal year, at the group home - and that's a picture of it there on the right - we provided 470 days of respite care to people from the West Prince community, compared to 156 days the year before, and to 76 days the year before that. That just shows the need for continued support and the support for housing needs for people with disabilities in our area.

Ann Mary, the lady on my left here, she came to us two years ago. At that time, she and her family thought that she would like to live in a community care facility, the Tignish Seniors Home Care Co-op, which is a great place to live. Anyway, we couldn't support that idea. You can look at Ann Mary, she doesn't belong in a senior's home. So she came to us two years ago for respite care until we could find appropriate supports and services for her. Well, she's still with us. She still didn't find what she needs. However, we'll be showing a video later and she'll be talking a little bit about her story.

We also have an Alternative Living Program where people in the community provide room and board and supervision. Those resources had been identified by the Residential Resource Committee which we had in West Prince which was formed in 1995 to strengthen the community's capacity to identify and support community-based residential options for people with intellectual disabilities, among other groups.

There was a partnership with West Prince Health Community Inclusions and the Canadian Mental Health. The number of resources in the area, however, in the past three years have diminished greatly, mainly due to the committee becoming inactive and

resource providers finding there's not enough incentive to provide services. So we also offer supports to people who live in apartments and we support one individual who owns his own home.

Over the past years the housing demands in West Prince have increased, while the housing options decreased. In 2004, there was a mother in her 80s in the O'Leary area who became seriously sick and she was unable to care for her 60-year old son. The supports were not available for her to suit their needs. So a group of parents got together at a meeting, invited Community Inclusions, and they asked us what residential plans we had in place for our future clients.

We knew that we had an aging population of parents who were caring for their aging sons and daughters. However, we had no formal plan in place to provide the impending demand for services. In order to develop a plan, we realized we needed to do a survey to determine the needs and to provide individualized planning and services. So we developed the future housing committee representing Community Inclusions board, staff, parent, self-advocate, to meet and to plan for long-term solutions regarding housing for people in West Prince with intellectual disabilities. Then we conducted an informal survey where I hit the street.

We identified 16 aging families who were caring for their aging sons and daughters with intellectual disability. We inquired about their current and their future needs and found that very little families had any type of plan in place. They thought that our current resources were inadequate, especially to meet the needs of the aging population. People in their 70s and 80s are caring for their family members. They live in fear that their family member will end up in an institution, they'd be neglected, abused, or that they'd lose their freedom. Those are things that families said to me.

Families expressed that they're tired, they're frustrated, they're afraid. They're taking one day at a time and they're hoping for the best. Well, that's not much, right?, for people to live a comfortable senior, in their senior years.

So Community Inclusions presented a housing proposal to the government for increased services, residential services, and supports, and we were asked to do a more formal survey. We had to identify the needs. So in 2007, last summer, again I hit the street. I interviewed 50 people this time, which included the 16 families that I interviewed in 2004 plus other parents, community resource providers, caregivers, and also self-advocates. We just thought we would talk to everyone.

We found that the issues remained the same. Some people actually have moved from the region due to lack of affordable, accessible housing and just through lack of appropriate housing options in West Prince. They had to move to Summerside and some moved to Charlottetown. There are 15 families in West Prince where parents or care givers are between the ages of 73 and 86 and are caring for the family members, representing seven people with intellectual disabilities. There's one family in the West Prince area who have three members still living at home with an intellectual disability over the age of 40, and those parents are aged 78 and 80. The resources are not there to accommodate their needs.

People under the age of 60 are living in community care facilities, others are using manors and hospitals and having to leave their community to go to Sherwood Home or to Camp Gencheff for respite care. People living in community care facilities or nursing homes do not qualify for DSP, therefore, losing out on age-appropriate day programming and community access.

Resource providers in our community have

decreased by 50% in the past three years due to the feeling that they're not compensated enough for the level of commitment that is expected of them, in terms of room and board, supervision, transportation, and any other responsibility that they happen to have with someone living in their home with a disability.

People in West Prince are at a risk of living in institutionalized settings if proper supports and policies are not implemented. There needs to be a no-admissions policy so that this does not happen. I'm not against community care facilities at all, and nursing homes - I think they're great places for the right reasons - but not just because you have a disability and have nowhere else to live, where you need the supports.

Aging parents and their family members are at risks in terms of safety in their homes, and it's our responsibility, as community and as government, to find solutions. In one particular instance there's a risk of overcrowding in a caregiver's home. She takes in respite care because she feels sorry they have no place else to go. She takes them in, and she also has people living with her and she's providing good care, but she's overcrowded and there's a safety risk there.

Self-advocates express that they feel lonely and isolated and they have the right to live in a safe, secure home in their own community with the supports such as budgeting, transportation, socializing, and companionship. Those are things they told me. Proper supervision for adults with disabilities regardless of their severity is a requirement, and it's a right, and should not be compromised because of lack of adequate funding.

Following are some of the recommendations as a result of the survey that I did. Number one, there needs to be flexibility to allow for independent planning based on individual needs. For example, associate families

where people can access room and board and have the supports needed. There needs to be support of apartments where if someone wants to live a semi-independent life, that they have the support that they can have living in an apartment.

Need to allow people to remain at home if they so choose to and still be eligible for supports. The level of supports vary if you're living with your parent or with a sibling, and then again if you're living in a community with someone else.

There needs to be supervised settings, for example, a small options home. That's what I think we have in Tignish where we have a home - our mandate is for four people to live there who need the supports. Most aging families, I found from interviewing them in West Prince, they want a supervised environment, they want a supervised home, as an immediate solution given the needs of their family members. Most of them need 24-hour supervision. Not everybody in West Prince needs that, but there are some who do, and families are asking for that, especially aging families.

Number two, there needs to be supportive decision making legislation where families and advocates can assist in making decisions when necessary. The DSP assessment needs to be advised to adequately meet individual's needs. Some people are assessed at \$1,000. Guess what? I have one person I work with moved out to the country. Transportation was very high. Because of that he's travelling on the school bus - and he's 45 years old - into his day program. That is not appropriate. It's because if he was assessed at a different level his needs would be met on a more age appropriate place.

Need to develop residential policies to ensure proper process. We strongly recommend that the residential resource committee in West Prince be revitalized to



identify new resources, ensure proper screening and safety measures are implemented, as well as accountability and sustainability.

There needs to be support to families to assist in future planning. I've talked to some families. They don't know where to start. They don't know who to go to or what to do to plan for the future for their sons and daughters. Again, they're sitting home and just hoping the best will happen, but they do need that. Estate planning and just planning for the future, so that their sons and daughters - that they can go on or go to their grave, so to speak, knowing that their sons and daughters are well cared for.

Groups. We need to partner. The Department of Health, Social Services and Seniors, parents, self-advocates, Community Inclusions, and private business people, they need to partner and work toward a housing strategy to ensure that immediate and long-term residential supports and services are in place to suit an individual's needs in the West Prince area, individuals with intellectual disabilities.

That's all I'm going to say for now. There's copies of the survey that I did. I don't know if you got a copy yet or you will, if you didn't.

**Kevin Porter:** They're going to be made available afterwards (Indistinct) -

**Ethel Ellsworth:** They are available.

**Kevin Porter:** - you will get a copy of that.

**Ethel Ellsworth:** This is the final copy of that survey.

**Kevin Porter:** The copies - sorry to butt in, Ethel. At the time when we did the surveying, we launched it in August at the Northport Community Centre, all the local MLAs in the region - I know, Paula, you

eventually got one, Robbie, Minister LeClair, and MLA Pat - got a copy. A copy went to the minister, so they've been out. Government has received the survey, but you guys will get a copy today. It's also on our website as well.

**Ethel Ellsworth:** I encourage you to read this, if you will, and if you need any clarification or if you have any questions, please do not hesitate to call Community Inclusions. I'm sure our number must be on there. If not, it should be.

**Kevin Porter:** I have another handout (Indistinct).

**Mr. Henderson:** (Indistinct) where are you at with that? That's been handed to government for some time now. Has anything been -

**Kevin Porter:** Do you want me to be honest with you?

**Mr. Henderson:** Yeah.

**Kevin Porter:** It's like trying to put a square peg into a round hole for the last four years. That's where we're at with it. We know the needs -

**Ethel Ellsworth:** This was just completed this summer past, I mean -

**Kevin Porter:** But we knew the need - we're doing what we're being asked to do and we're playing in the role that we want to play. We want to work this out in a cooperative and in the spirit of goodwill. But I got to tell you, that's really hard to do when you have an 80-year old parent or person call you up and say: Listen, where can I - I don't have any respite from my 76-year old sister. I just need a break. I feel that I'm not doing my job, and I have to tell them: Well, I don't know. You know where that person went? To that overcrowded resource in the community. It's not

something that we support, but what are folks going to do? We can't control that.

So we know what the needs are. Bridget will get into this a little later on. It's not a West Prince thing, it's not a Prince Edward Island thing, it's a Canadian-wide - probably North America and beyond. People with intellectual disabilities are living longer. They're living with their aging parents. Their resources just aren't there and we're seeing the result of that through people leaving or people going into manors and stuff like that.

We don't knock those facilities, but it's not appropriate housing. People in the know, or that should be in the know, have approached us with that many times and it's been frustrating. So we know what our needs are. We know they're immediate. They were immediate two years ago and we need some - really need some - action on it.

**Mr. Henderson:** I think the other thing that I sort of see about it is when we're putting people in not age-appropriate facilities, we're also taking up the facilities that should be used for somebody that is age appropriate.

**Ethel Ellsworth:** For the right (Indistinct).

**Kevin Porter:** That's right.

**Mr. Henderson:** And we're putting people in more costlier situations to the taxpayer, too.

**Kevin Porter:** I think you'll see through those recommendations that it's not all about bricks and mortar. We're not looking for that most expensive stream of money. We're trying to be responsible. In other words, change some policy or incentives where people in the community can take more people in or new people will come forward. Support families more that are already caring for sons and daughters that

maybe that age isn't such an issue but let's - it's almost like: That person is your son or daughter, you have to look after them forever and pay the price. That's not very fair

I know I have three kids of my own. I have three wonderful boys, but do I - are they going to be living with me when they're that old? I hope not. I hope they have their own lives and their own supports to be able to do that. Why is it any different for somebody with supporting somebody with intellectual disability? It's just not right. It's not right.

**Ethel Ellsworth:** Just one more point while we're talking about that. In the past year, there's been two people in their 50s - a year or two years - where family that worked around government I guess, or whatever - anyway, they were placed in community care facilities and they're not getting along very well there. Actually, they're regressing. Socially they're regressing, and mentally and physically, so it's sad to see that.

That's only because we don't have the proper supports in our area to suit their needs. We're not saying we just want a group home or a supervised setting, yes, some do, but most don't. So there's the different supports to suit your needs.

However, that's all I'll say for now. This is the survey results. Of course, feel free to talk now. You can call myself or you can call Kevin at the office and we're willing to talk or you can ask any questions now if you want to. If you have any questions, if not -

**Chair:** There's actually a couple of questions.

**Ethel Ellsworth:** There's a couple of questions, okay.

**Chair:** Mike Currie and then Cynthia Dunsford.

**Mr. M. Currie:** Thank you, Chair.

Ethel, I'm interested - I know everybody has a similar type of situation as you do in West Prince and every riding in PEI - but on the estate planning when you did the surveys, when you go into a home where there's two or three people that are 40 to 60 years old still being cared for by parents, how do you - like, the estate planning, they're there because the parents protect them, want to see them maybe in that environment or looked after. They don't want anything to happen to them. How do you get into the estate planning with people of that age now that - are you going to guarantee that they're going to live in this house and you're going to care for them 24/7?

**Ethel Ellsworth:** They have to be very creative in how they plan. However, I remember going into that house about five years ago and I said: Do you have any plans in place for your - they have three daughters, actually. She said: No, as long as - they were healthy at that time - as long as we're alive, our - well, they call them children - but our daughters will remain living with us as long as we're here. I said: But what about when you're not here? You know, it gets them. We see that. We see it. They don't see it as well as we do that they need that planning.

**Mr. M. Currie:** That's the point I was trying to make, I guess.

**Ethel Ellsworth:** Yeah.

**Mr. M. Currie:** So what do you do in that situation now? If those parents were to - and I don't wish that - but pass away, so there's three adult daughters that are staying there. Are they taken to a community care or do you guys move in?

**Ethel Ellsworth:** There are some extended family. In fact, there are some siblings in this case who will do that in the short term, and probably then the planning will start.

Because you're right, they're 78 and 80 years old. Now, you know, it's (Indistinct) -

**Kevin Porter:** The other thing too, and I'll just add -

**Ethel Ellsworth:** Sure.

**Kevin Porter:** - if we had, if they had, if there were appropriate resources in the community, I think they would feel differently as well. Right now, they don't see that there, so that's - I agree with what you're saying too, that there's a real bond and maybe they're not into the estate planning, but part of the reason is because they don't see any of the services there.

If there was something in place for them, or at least a light in the sky that said: Okay, we're going in that direction, then I think it would be a little easier. Maybe that would get the ball rolling.

**Ethel Ellsworth:** The planning needs to start in the beginning. At a very young age the planning needs to start. Parents don't do that because they think, you know - and Bridget may be able to enlighten you on (Indistinct).

**Mr. M. Currie:** Most of the ones that I ever got involved with, it's a very sensitive -

**Ethel Ellsworth:** Yes, it is, very.

**Mr. M. Currie:** - conversation to have with somebody to suggest that your child should go to another facility.

**Ethel Ellsworth:** It is.

**Mr. M. Currie:** If you want to lose votes fairly quick, that's the one to get into.

**Ethel Ellsworth:** However, well -

**Mr. M. Currie:** Because it's just not one - the bonding is there -

**Ethel Ellsworth:** I agree with you.

**Mr. M. Currie:** - they're going to look after him. Nobody in government can look after my child as good as I can.

**Ethel Ellsworth:** The hardest thing is when an extended family member comes to me and says: So-and-so has to leave. I have this situation in our area, where the mother is 85, I believe, and he was 60. They are so bonded and so close that she said: I can't leave him. Where you go, we'll both have to go together. It was a safety issue for both of them in that house. Adult protection came and talked (Indistinct). We all worked together and said - that was about four months ago. Since then, he died. Well, that solved the problem, but it's unfortunate, but that's what happened.

But you're right, there was such a bond there. She said: I can't leave him. We have to go together. So eventually, he did go to the manor and went to the manor and I think the separation caused a lot of grief, and he did die on Christmas Day.

**Kevin Porter:** The other thing too, and Ethel brought this up, the legislation that was developed years ago and now it's kind of coming a little bit to the forefront - and hopefully it's going to go to the House at some point in time, it'd be nice to see it go in the spring - the supported decision making and guardianship, if parents do pass away and you ask where those people are going to go - without that now they're going to go wherever their families, if they have families, choose to put them. Sometimes, that might be the appropriate place. We've seen cases where it's not.

We had a person set up in, we felt, a very nice home in the ALP Program. Unfortunately, there was a bit of a - families weren't getting along with one another and that person is now living in a community care facility. Guess what? They don't go out

during the day. This person has gained a lot of weight. There's no stimulation. So what I'm saying is that that supported decision making will help the process. When we talk about inclusion and for those people who are capable, they should have the right to have an idea where they're going.

This person didn't. They were taken from a home that they quite enjoyed living in and they were put into a community care facility.

We're not knocking those facilities. I think they do a great job for the appropriate people that go there. So I'm hoping that when that legislation goes forward that something's going to happen with it. Because right now, they're just - it's not in place. So people don't have any kind of a say or right - or at least a lot of them, to where they're going and that's just not right. That's not inclusion.

**Chair:** Cynthia.

**Ms. Dunsford:** I just have a couple of questions about the surveys. You had mentioned that you had done a survey originally.

**Ethel Ellsworth:** Yes, in 2004.

**Ms. Dunsford:** In 2004, and then you were sent back to do another one that basically yielded the same results. So I can understand your frustration with the system.

**Ethel Ellsworth:** The same and greater results, yes, because by this time -

**Ms. Dunsford:** But basically, the results were saying the same thing and the recommendations were basically the same as well.

**Ethel Ellsworth:** Yes.

**Ms. Dunsford:** I guess by pointing that out

with the previous government would have been in 2004. But what was your sense at the time of why that took place? Because if we're looking at systemic problems which I sense a lot of the frustration is around - if not all of it - then that's what we have to kind of zero in on.

So why is it that you think you were sent back to go do another - like, is it because it wasn't on the right paper or what was it?

**Kevin Porter:** Do you want me to?

**Ethel Ellsworth:** Yeah, go ahead.

**Kevin Porter:** I'll speak a little bit to it. I think one of the things - and maybe I'll do it here - and then Ethel, you can add in instead of at the end. The last thing that I want to talk today or talk to you folks about today and share with you was process, how things happen.

We don't expect government to do everything. That's not sustainability, that's not community capacity building. But you guys have your footprint on a number of things. We have a number of partnerships with government. This is a partnership here, just you guys funding us, getting funded through government. We carry out the day-to-day activities, but that process needs to improve. We need to pay close attention to better maintaining the relationship and partnerships with NGOs such as ours.

As I mentioned in the past, when there have been internal changes in government we have often been left on the outside looking in regarding projects that are mutually worked on. Now we're not operating government - I know it's a difficult job - but a lot of people put, on both sides, put time and effort into developing relationships.

**Ms. Dunsford:** I think by saying on both sides - sorry to interrupt - but when you say on both sides, that's a problem right there.

**Kevin Porter:** Yeah.

**Ms. Dunsford:** It's not sides.

**Kevin Porter:** No, no, that's not my problem. That's how I worded it.

**Ms. Dunsford:** I understand that.

**Kevin Porter:** I believe in what you're saying.

A few examples. Government initiated NGO discussions a few years ago to help iron out some of the issues that we were dealing with. The process had three components. The first one was to deal with a funding crisis. This was a great initiation. I applaud government for it. It was the first to deal with the funding crisis that many NGOs were experiencing at the time. The second was to look at standardized contracts and accountability and all those kinds of things. The third was long-term planning.

During program renewal this process was stalled for a time. Like, for six months we didn't hear anything, nothing. After it started again - which was great - and then it's been dormant since the spring election. There's been hints of things, there's been informal talks, but nothing official, okay? That's what I'm talking about. Because housing falls in there. The day-to-day goings-on of people's intellectual - it all falls in there. So what happens is, you've got to start and stop, start and stop. Then when we get going again, it's going to take a few meetings to get back on track. So it's a flawed process. Okay? That's one example.

The other thing I'll mention to you was - and this happened during - Ethel mentioned the Residential Resource Committee, and that was a great committee. I believe it was something that was only done in West Prince. We were proud of it. It was a partnership between the province, us, Canadian Mental Health, and so forth,

where families were, people that were interested in providing respite for our population. They were screened, monitored. There were fire checks done. It was a great thing. There were policies in place for that. It went by the wayside. I don't know how many times that we voiced: You need to get that back off the ground. You need -

**Ms. Dunsford:** Have you been given any indication at all that they're headed in that direction? Or that -

**Kevin Porter:** No.

**Ms. Dunsford:** There's been no communication between your group and -

**Kevin Porter:** No.

**Ethel Ellsworth:** Just one, just one point I want to make. I did talk to Steve McQuaid, and Steve McQuaid is doing a study. That was one of the things we talked about. We talked about how it might look like - it may not, chances are it is not going to look the way it did before, but we may have the same kind of policies but they might look different. So there is some talks underway.

**Kevin Porter:** But that's Steve, that's not, he's going to make those recommendations.

**Ethel Ellsworth:** He'll make the recommendations. But at least, it's starting there.

**Kevin Porter:** Okay, that's not anybody in government.

**Ethel Ellsworth:** But it's starting there. Somebody has to start.

**Kevin Porter:** But my feelings are that it's dead in the water right now. That's another example of when things change within government - again, I can't stress enough - I don't know everything that goes on. I don't have an appreciation. I think it must be very

difficult but don't we owe it to the people that we serve, be it the citizens of PEI, people with intellectual disabilities, to do things better. That's you guys, that's me, that's everybody.

**Ms. Dunsford:** What's behind my question is to identify what those systemic problems. It's not a matter of will. Nobody around this table here is going to say that this is -

**Kevin Porter:** Listen, I hope so. I hope we're not sitting here -

**Ms. Dunsford:** Oh absolutely.

**Kevin Porter:** - in three years time and I'm telling you the same thing. I'm only saying that because I have a history of that, in a sense that nothing has happened. We're in a crisis. We were in a crisis five years ago. So, you know what I mean? It's time to do something, or people, it's just going to get worse. You have all these parents. We have people that are dying. We have people that are getting older. The problem is not going away.

**Chair:** Pat.

**Mr. Murphy:** Just on the housing portion of it. Is there adequate housing in the cities now, like in Summerside and Charlottetown? Is it a problem here too, or is it just in West Prince?

**Ethel Ellsworth:** Bridget will be talking on it provincially, so I mean, like I was just talking West Prince, but I'm sure there's not. Anyway, Bridget will get -

**Chair:** I can answer that in Summerside. I mean, certainly, there's a shortage and the issues are the same.

**Ethel Ellsworth:** Oh yes, the issues are the same across the Island.

**Bridget Cairns:** Currently right now - I'm

in the Montague area - the group home is full, so you'd have to wait for someone to die in that group home in order to get a spot.

**Ethel Ellsworth:** Oh yeah, that's the same in Tignish. It's the same in any group home in Summerside, too.

**Chair:** Okay, Paula Biggar and then Mike.

**Ms. Biggar:** Something I've heard a lot from people, families, is the fact that there isn't a lot of incentive dollar-wise for people to take their child for a weekend. I hear that from the people also that are respite caregivers that they have to take a lot of activity money out of their own pockets. If you have some figures, if you could share on that.

**Ethel Ellsworth:** It seems that the respite dollars vary across the Island. Now I know that some people will differ with me, but for someone up west, anyhow, they'll say it's \$35 for 24 hours to take someone in, \$35 a day. Well, now people in Summerside are saying that it's 45 and it's 50. I guess they can charge whatever they want now with the GST in one way.

**Bridget Cairns:** When it was regionalised, depending on who your worker was, it did vary. I've had families that had to pay \$75 a day. So it's very inconsistent implementation of the policies across the region.

**Ms. Biggar:** Because what I'm hearing is from the perspective of the respite caregiver, it is a disincentive for them to be involved in that because they're paying out of their own pocket as well -

**Ethel Ellsworth:** Exactly.

**Ms. Biggar:** - to provide over and above what they get for the 24-hour service.

**Ethel Ellsworth:** Well, they're not making

anything at \$35 for 24 hours a day with supervision, care, meals.

**Kevin Porter:** They're not in it for - I think most people do it because they want to do it, but in saying that, you're right, the incentives aren't very great. You know what? Maybe there has to be some more dollars put into that. But there also has to be some - so what are the costs of not doing that? Well, MLA Henderson there mentioned people having to go to manors and hospitals and all those kinds of things. That costs an awful lot of money, much more than if a little more incentive was given to people.

So that's where there has to be a real vision. People have to step back and go and take a real look at it through the lens and that hasn't really been done. Do you know what I mean? With a little bit of long-term planning, yeah, it might cost us a little more money up front, but I tell you, if it continues the way it is, with people having to go into different spots, it's going to cost an awful lot more.

**Ms. Biggar:** Thank you.

**Kevin Porter:** I'll mention too, just a little bit, the transportation thing that's going on. I know their study is near completion and a pilot is going to be put forward. I don't know what support that is going to get from this government. But I will tell you that for our folks travelling on school buses - I worked in employment before I was executive director here at Community Inclusions - especially in a rural area, people cannot get out to go anywhere, or a lot of people can't, whether it's work, whether it's social outings, seniors wanting to get out, things like that.

For our folks, they have to come - and we appreciate it very much, don't get me wrong - people can come on the Western School Board to get to our facilities. If they didn't

have that, they couldn't come.

So is there a cost to establishing a transportation network? I say it because my ears perked up when I heard it the other day because Tignish was mentioned as well. Charlottetown, Summerside, but also Tignish lumped in. My thing is if you don't fund it, the cost is greater. If you don't fund it, the cost is going to be greater because the quality of life, people aren't going to be contributing taxpayers - that's where you have to step back and have some vision with (Indistinct) and really have a long look at it.

Transportation is huge. That's something that I've kind of added on here, but it's in the news now. I encourage you very much so to have a long look at that and consider the cost of not implementing it. It might cost you something to put it in place, but it's going to cost you more, believe me, in not putting it in place.

**Chair:** Okay, we have Mike Currie and Rob Henderson and I think that -

**Mr. M. Currie:** Ethel, does a facility have to be licensed to do respite care?

**Ethel Ellsworth:** No.

**Mr. M. Currie:** You don't?

**Ethel Ellsworth:** Not to do respite care, no, anybody can do it. But again, getting back to the Resident's Resource Committee that we had, their policies dictated safety screening. They've applied and we screened and had a criminal record check and made sure they had CPR, First Aid, followed the fire safety codes and then the continued monitoring. My job is to monitor those placements.

But no, they don't have to be - if you have more, I believe, more than four people, is it, that's not your family, you have to become a licensed -

**Kevin Porter:** You have to have a license.

**Ethel Ellsworth:** - become a licensed facility.

**Mr. M. Currie:** A licensed facility, are they allowed to do respite care?

**Ethel Ellsworth:** Yes.

**Kevin Porter:** Yes.

**Ethel Ellsworth:** They can do respite care, yes.

**Mr. M. Currie:** They do it for \$1.45 an hour?

**Ethel Ellsworth:** No, no.

**Bridget Cairns:** No, the community care facilities -

**Mr. M. Currie :** Thirty-five dollars a day.

**Bridget Cairns:** - get more than what families -

**Ethel Ellsworth:** No, no.

**Mr. M. Currie:** Pardon?

**Bridget Cairns:** The community care facilities would get their daily - much more than what families would get.

**Chair:** That's what he's trying to say, I think.

**Kevin Porter:** That's the difference in policy. Those are the kinds of things we're talking about. They would, you're right -

**Ethel Ellsworth:** For an individual to live in a community care facility it's \$17,00 a month, but if they were to live in a community with you or I, we would get - the cost would be \$470 a month, I believe it is. If they live with a sibling it's \$110 a month.



If they live at home with their families, it's nothing.

**Mr. M. Currie:** So if they're living at home

-

**Ethel Ellsworth:** At home, it's nothing. Families don't get any room and board.

**Mr. M. Currie:** If they're living, okay, living with their family and then they want to go away for the weekend -

**Ethel Ellsworth:** Yes.

**Mr. M. Currie:** - and put their child into the community care, they pay \$35 a day.

**Ethel Ellsworth:** Not community care, in the community. If they came to the group home, it's \$35 a day.

**Mr. M. Currie:** There is other group homes.

**Ethel Ellsworth:** Or other group homes, yes, or in the community. Most people are using resources in the community, caregivers too, and it's \$35 a day. But people are now saying that that's not enough.

**Bridget Cairns:** So some families might not be eligible for more than \$35 a month. It does if they're going to get whatever they need or what they want. It's what you're eligible for.

**Ms. Biggar:** They may all get one respite care, perhaps a day per month, is what you're saying.

**Ethel Ellsworth:** Because a respite care provider can say: I want \$50 and I will take your son or daughter for \$50 a night. Okay, we'll give it. However, what happens, the individual with the disability is losing service because now they have to cut into the next weekend in order to get one

weekend, you know. So that's what happens. They lose out in the end.

**Chair:** Okay, Rob and then Sonny.

**Mr. Henderson:** Thanks, I appreciate your presentation here, Ethel, Kevin and Ann Mary.

As far as we talked about facilities and the shortage of facilities and some sort of a supported housing or supervised housing arrangement, do you have any kind of an idea, like how big a facility is required? Any idea around that side of it? Or how do you see this supposed facility to look like? (Indistinct).

**Ethel Ellsworth:** The immediate solution like I just said, there are some families, and especially aging families, they have sons and daughters with high needs. They would like to see a group home setting, a supervised setting. I don't like to see any more than four people in there because, first of all, there's a staffing issue. Any more than four people - depending on their needs too - any more than that, you're looking at an institutionalized setting and it's just not -

**Mr. Henderson:** Trying to get away from that.

**Ethel Ellsworth:** Yeah, I mean if there were eight people who need a service of that kind, we could rent two homes or something or two duplexes or rent two homes or whatever.

**Kevin Porter:** Yeah, the models that we have in place, we have it for eight. That would be pushing it.

**Ethel Ellsworth:** That was a duplex.

**Kevin Porter:** That would be double staffing throughout some of the day with people going out through the day, being home in the evenings, weekends, holidays,

that kind of thing. But we have three models in places: one rent, one fix something up, rent, and lease from somebody, I mean the other, build a place ourselves and staff it and operate it.

The ideal one would be -e don't want to have to look after the ownership of a building. We have a good arrangement with CMHC with our Tignish Group Home. We look after the staffing of the day-to-day operations. They look after the big ticket items and the building, per se. But we have three models in place now in the government that we put in along with - when we did the housing survey, we also had a follow-up meeting and you were at that meeting, and we provided you guys with some models. Talks are slowly occurring there, or happening, I guess.

**Mr. Henderson:** But if you're looking at say, 16 people, or 16 families between the ages of 73 and 86, the parents are looking after people. I mean, you're looking at three or four facilities.

**Ethel Ellsworth:** Well, we would hope that they would not all going to go through - well yes, exactly. Well, that's what the need is.

**Kevin Porter:** That's what the need is. O'Leary, Alberton, those would be two centres. We definitely would need -

**Ethel Ellsworth:** Some of those could also, if the community resources were enhanced in the community and given more incentive to take people in, then some of those people would move there. They're not all going to want to go to a group home.

**Mr. Henderson:** Yeah, so you don't necessarily - that's right.

**Ethel Ellsworth:** Anymore than four people and you're single staffed. That kind of dwindles down on the individualized support that, that happens there. We have

four people at - well five, when Ann Mary is there. Ann Mary lives a different, a more independent life, in one sense. However, we do have some one on one support, but we work and we manage it so that people have as much individualized lifestyle as possible to suit their needs and that's what we do.

**Mr. Henderson:** Yeah, I certainly see it as a huge issue in West Prince and I think it's a shame that we're, at this point in time, that we're still talking about it. I hope something happens fairly quickly.

**Chair:** Thanks, Rob. Sonny and then Cynthia.

**Mr. Gallant:** Just backing up to the respite care, who pays for that? Does the family pay for that or?

**Ethel Ellsworth:** Families get it through their DSP plan, again just through the assessment and family - I'm looking at you, Bridget, because you're going to be talking about that. Yes, they do. Money goes to the - in most cases, not all the time, not all the time, but that was the first, when the DSP was first, came into place, money was given to families to buy a service. So they would be allocated so much dollars a year to provide a service, a respite care service, for instance.

Some people didn't use it. They got the money in their hands and they didn't use it. Yes, they are, in some cases. In other cases, it's not where we saw that they weren't using it. Sometimes when we went back to do our review, they kept it back, the DSP worker or the social services and then, for instance, if they came to the group home, I would make an application for them for that respite, so both ways. Some families do, some don't. Not out of their - it comes in their plan, in their GSP plan.

**Chair::** Next, Cynthia.

**Ms. Dunsford:** Just a point and a question, when listening to, I guess, for lack of a better term, the predicament that we're in here. It's very similar to the situation that foster parenting on PEI has been in over the last few years: extreme frustration over the way the system has in so-called processing things. It just sounds very similar.

I had a little bit of involvement a few months ago just kind of trying to get the sides back around the table, so that were no sides any more. Is that something that we can say is going to happen from this? That that can occur around a table with the people that you need to be around?

**Kevin Porter:** I hope so. We're certainly ready. We've been ready for awhile. We would like to see that happen.

I mentioned before that your guys' footprint is over a lot of things and you can be that facilitator to bring groups together. So I would hope that that would be a result. The disabilities, not just the Disability Support Program, but just disability supports, in general, that's under review as well and that's good. Both Bridget and I sit on that reference committee or that steering committee, so that would provide you guys with some good information too. We're hoping to have something ready for you guys in time for when the House sits in the spring. That's going right across the Island. We'll be talking to people and getting their views, so that should help as well, to flush things more out, yeah.

**Bridget Cairns:** But what will be disappointing is after another yet, consultation, nothing happens. I would like to see disability be part of a government priority similar to the family violence and it has to happen, because we can't just fix a few DSP policies. It's the system.

**Ms. Dunsford:** I couldn't agree more. If

there's any hope to be provided, I think that you do know I know the progress is happening with the foster parenting and a lot of that has to do with addressing those kind of problems. It is happening, they are improving, so that is where, that's where we have to start. I think we agree on that.

**Ethel Ellsworth:** Okay, just to finish off here, I just want to thank you all. I certainly appreciate coming here and presenting to you today, and thank you very much.

**Kevin Porter:** Do you guys have any time to see that little 10-minute video?

**Chair:** I was just going to ask if you would run that.

**Kevin Porter:** I can do that. Ann Mary is here. She was a big part of that. Is that okay?

**Chair:** Yes.

**Kevin Porter:** Is that okay, Bridget? So we'll bring that up and then we'll finish off with that.

I, as well as Ethel, would like to - we'll see if this starts - yeah, just let me bring this back. That will go full picture here in a second. Again, this was shot in the spring. We showed it out of their AGM and it talks a little bit about our group home in Tignish and also the situation with regards to housing. It's pretty low tech. I was on camera so it's like watching the *Blair Witch Project* a little bit. Ann Mary did a great job. Ann Mary and I did this, and Ethel, and we had somebody actually do some editing for us. So bear with me, I think you'll get the message.

*[A DVD was shown; there were various voices]*

**Unidentified Speaker:** In February of 2006, Ann Mary Perry moved to the group home

in Tignish as part of a transitional plan for a more independent living arrangement in the community. Over the past 20 years, Ann Mary lived in eight different room-and-board settings in different communities of West Prince. Since Ann Mary has been living in a fully supervised environment in a group home, a lot of her fears have subsided. A year ago, she was afraid to walk up the street for fear that she could become lost.

**Ann Mary Perry:** Since I moved here (Indistinct) and I'm really happy to be in a group home. I'm really happy with the people that (Indistinct) give you your breakfast, they make sure your clothes are clean, and you're well taken care of, and thank you very much.

**Unidentified Speaker:** So do you want to talk a little bit about your day? What's your day look like (Indistinct)?

**Ann Mary Perry:** I wash dishes.

**Unidentified Speaker:** (Indistinct) do you go out (Indistinct)?

**Ann Mary Perry:** Yes (Indistinct).

**Unidentified Speaker:** Okay, where do you go in the mornings?

**Ann Mary Perry:** Go for a walk at the store.

**Unidentified Speaker:** You do?

**Ann Mary Perry:** (Indistinct).

**Unidentified Speaker:** During the week (Indistinct).

**Ann Mary Perry:** (Indistinct) from Monday to Thursday.

**Unidentified Speaker:** And that's it?

**Ann Mary Perry:** (Indistinct).

*[There was a technical malfunction]*

**Kevin Porter:** We did watch this, Ethel, through, and it worked great. Let's try a different way here. If it doesn't work, it's unfortunate.

**Ms. Dunsford:** Do you have copies?

**An Hon. Member:** Is it on the web site?

**Kevin Porter:** I can certainly - it's not on the web site, but I certainly don't have a problem leaving it for you guys to view it later. But it should play. Let's try it on (Indistinct) DVD.

**Ms. Dunsford:** (Indistinct) the web site, did you say?

**Kevin Porter:** Excuse me?

**Ms. Dunsford:** It's not on -

**Kevin Porter:** No, but you're giving me another idea to put it on. Yeah, it's not on the -

**An Hon. Member:** (Indistinct).

**Kevin Porter:** Actually, it's not a bad idea. Sorry about that, folks. If this doesn't play, it does the same, we'll just turn it off and I'll leave a copy here, for the sake of time.

*[The DVD began playing from the beginning; the transcript is repeated here]*

**Unidentified Speaker:** In February of 2006, Ann Mary Perry moved to the group home in Tignish as part of a transitional plan for a more independent living arrangement in the community. Over the past 20 years, Ann Mary lived in eight different room-and-board settings in different communities of West Prince. Since Ann Mary has been living in a fully supervised environment in a

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**Ann Mary Perry:** (Indistinct) from Monday to Thursday.

**Unidentified Speaker:** And that's it?

**Ann Mary Perry:** (Indistinct)

**Unidentified Speaker:** Ann, how do you get there?

**Ann Mary Perry:** (Indistinct) bus that comes to pick us up (Indistinct).

**Unidentified Speaker:** (Indistinct) then?

**Ann Mary Perry:** I have my supper, then I go for a walk. I go for a walk a lot.

**Unidentified Speaker:** Do you feel okay walking (Indistinct)?

**Ann Mary Perry:** Yeah. I'm really safe to walk on this road. (Indistinct).

**Unidentified Speaker:** So where else do you walk?

**Ann Mary Perry:** I walk to the store (Indistinct).

**Unidentified Speaker:** So what about if you have appointments?

**Ann Mary Perry:** I walk to my appointments myself.

**Unidentified Speaker:** (Indistinct).

**Ann Mary Perry:** (Indistinct).

**Unidentified Speaker:** When did you start going to meetings?

**Ann Mary Perry:** Just last week. (Indistinct) to take you home (Indistinct).

**Unidentified Speaker:** (Indistinct).

**Ann Mary Perry:** (Indistinct) on Tuesday, Wednesday, and Thursday in Alberton. (Indistinct).

**Unidentified Speaker:** During the past year a very natural and inclusive thing happened. While leaving St. Simon and St. Jude church in Tignish, she met a couple, Gerald and Mary Keough, who offered to drive her back to the group home and then volunteered to pick her up and drive her back each Sunday.

**Unidentified Speaker:** When I met her I was going to church on Sunday morning and

(Indistinct) ball game just last July. (Indistinct) and I said no, (Indistinct). That's the day I met Mary and (Indistinct) the church. The first time you went to mass here in Tignish, was it? She was a little bit nervous so she sat with me, and on the way home I said: We'll pick you up on Sunday for mass. We've been doing it ever since. She appreciates it, I know she does. She always thanks us, thanks us and thanks us.

**Unidentified Speaker:** (Indistinct) Ann Mary, how do you (Indistinct) with that?

**Ann Mary Perry:** (Indistinct).

**Unidentified Speakers:** (Indistinct).

**Unidentified Speaker:** Ann Mary, when you look back a year ago, (Indistinct).

**Ann Mary Perry:** No.

**Unidentified Speaker:** Why?

**Ann Mary Perry:** (Indistinct). (Indistinct) couldn't go anywhere, I was too nervous (Indistinct).

**Unidentified Speaker:** What changed?

**Ann Mary Perry:** (Indistinct) used to just stay at home. I usually saw people (Indistinct) and the people in St. Louis (Indistinct) always had a smile on her face. Now that I'm in Tignish (Indistinct) smile on my face (Indistinct), how are you today.

**Unidentified Speaker:** So, do you feel that you still have some fears? (Indistinct) fear of being alone.

**Ann Mary Perry:** Yeah, I'm often scared to be alone.

**Unidentified Speaker:** Do you still have a fear of being alone?

**Ann Mary Perry:** Yeah, yeah.

**Unidentified Speaker:** And do you worry about being alone? Do you ever worry about having to get off the bus and (Indistinct)?

**Ann Mary Perry:** No, that don't cross my mind.

**Unidentified Speaker:** No.

**Ann Mary Perry:** There is always somebody here. (Indistinct).

**Unidentified Speaker:** So you feel that you need to be in a place where there's staff and (Indistinct) because of your fears?

**Ann Mary Perry:** Yeah, and (Indistinct). (Indistinct) cookies (Indistinct). if I mark it down, I'm okay. If I don't mark it down, I'll forget, I'm forgetful.

**Unidentified Speaker:** So are you happy?

**Ann Mary Perry:** Yes I am.

**Unidentified Speaker:** You are. (Indistinct).

**Ann Mary Perry:** (Indistinct) people are really nice.

**Unidentified Speaker:** Is there anything we can do for you to make your life better and have more independence?

**Ann Mary Perry:** No. (Indistinct) I always dream of going back to (Indistinct).

**Unidentified Speaker:** And you went? (Indistinct)

**Ann Mary Perry:** Yeah, last week, last Thursday.

**Unidentified Speaker:** (Indistinct).

**Ann Mary Perry:** (Indistinct) walk down and they take me home. They say that I've no reason to be scared.

**Unidentified Speaker:** So you're home today, so what are you going to do this morning?

**Ann Mary Perry:** (Indistinct) store (Indistinct).

*[The DVD ended]*

**Chair:** Okay, first of all, I'd just like to say that the presentation was very well done. Certainly, you're very passionate and devoted to making things better with the housing situation in West Prince. I think it was unanimous around the table that you're not in an exclusive situation in West Prince. I think we've identified that communication is another issue. The point was well taken.

So I'd like to thank you all for coming. Ann Mary, it was wonderful to see you again. Ann Mary and I are old friends. We've done some camping in the past together, done some shopping in Moncton on a few occasions in the past. So it was really good to see you, Ann Mary, and good luck. Thank you very much for coming in.

**Kevin Porter:** Thank you very much for your time.

**Chair:** Okay.

So Bridget, is it Bridget?

**Bridget Cairns:** Yes.

**Chair:** Okay. You're going to go ahead.

**Bridget Cairns:** Depends on who you're talking to. I'm also known by Cathy and that's probably where - Jim's probably wondering: Bridget? Yes, family call me Cathy. Bridget was not an easy name growing up in the 1970s, though it's very popular now.

Can you hear me? I've got a cold. My co-chair on the Disability Services Review

Committee decided that I needed to share his cold, so I now have it. Can you hear me well enough?

**Chair:** Can everybody hear? You're representing the PEI Association for Community Living?

**Bridget Cairns:** Yes, I am.

**Chair:** Okay. Are you here by yourself or do you have someone else here with you?

**Bridget Cairns:** I brought two of our members, Mabel and Jim Thompson from Summerside.

**Chair:** Welcome.

**Bridget Cairns:** Thank you for coming.

So again, good afternoon. My name is Bridget Cairns. I'm the Executive Director for the Association for Community Living. I'm also a parent of a 13-year old boy with autism. He was diagnosed with autism at the Hospital for Sick Kids in Toronto when he was two, but doing very well in grade 8 in Montague.

The PEI association, if anybody's not aware, is a non-profit organization started in 1955 by two parents. I could possibly speak on any particular issue with regards to disability for the next two weeks, if you're willing, but today I'm here to talk about aging parents caring for their son and daughter at home. Though I will put the invite out that if you wish to talk about any other issue I'm always willing to talk about the issues affected by families.

So, with Kevin, I opted not to go technical because I always have difficulty with presentations, so I thought I would just hand out my presentation here and not opt for technical advancements there. So if you just want to pass them down.

**Unidentified Speakers:** (Indistinct).

**Bridget Cairns:** I always have problems with power point. Plus with paper, you can always just make your notes, and if you have any questions following the presentation feel free. Oh, is there one missing? You can share for a bit. Sorry about that.

**Paula Biggar:** I'm familiar with it.

**Bridget Cairns:** Okay. The Association has, for many years, consulted and asked our membership about issues, but our latest consultation was at the Linkletter in Summerside in 2006. Many of the issues that we heard are similar to what you've heard Kevin and Ethel speak about. I won't go through them all because I'm sure that we already know where that's going from.

We're running out of time. We need respite care. You're offering us management on seniors. One of biggest issues: My income has decreased drastically, but DSP hasn't been indexed since its implementation.

So, you know, we can go on with this here, but I think the most important one - and I was trying not to interrupt and answer some of the questions that you're asking Kevin and Ethel - was the reason why families aren't doing care planning is of various reasons. One of it is it's a generation issue. The generation of that time was the mothers took care of everything, the fathers went out to work. So that's why those aging parents are still caring for their son and daughter at home, because that's how they were raised and they know that that's their job. To say that I can no longer take care of my child is very difficult for mothers to do that now, and fathers think that mothers are going to take care of it.

I'm not trying to make fun of generations or male-female. It's just the way it is. That's one of the reasons, or I would think one of

the main reasons why nothing is done.

The other one is superstition. Families are superstitious to make wills and estate planning for fear that after they've done it that they're going to pass away. It's the way it is.

So I've got (Indistinct) statistics on the next slide, the same ones that you probably have seen many times, but I thought I'd provide it to you just in case you needed that for your information. Of course, everybody has unmet needs.

I just gave you a bit of a background on why families are important. I think we need to remember that. Though families say that they don't have enough support or they have so many unmet needs, we still have to remember that families are essential to a person's life.

So, what we heard, or what parents, their concerns about - and I tried to do it where it was helpful, so I did issues, implications and solutions for you guys. So out of the consultation the top priorities, the three top - because the list was extensive, we asked families, okay prioritize for us. So I'm going to present to you the top three priorities that families wanted us to address.

"We are uncertain who will provide care when we're no longer able. There is uncertainty that the government and our neighbours truly don't understand our situation." So the issue is 80 to 90% of our population do not have a succession plan in place for the dependent son and daughter.

In 2003, with the assistance of the UPEI Senate for Aging and the federal-provincial funding that we got for Community Inclusion, we were able to identify 400 aging families across the province who are still caring for their son and daughter at home. That would include Ethel's 16 and then 50. Of course, the most were in



Charlottetown, then Summerside, and then Souris, Montague.

Implications. So what's going to happen? We have 400 aging parents still caring for their son and daughter and 80 to 90% of them do not have a plan. It's the worst day of my life when I go into the office - and I've had probably about three in the last month - where I have the father calling in and saying: My wife took care of him, I don't know what to do, come, get him, please. It's the worst way to start your day. To have a father call - I can just imagine him standing at the phone and trying to dial the number to call me and ask me to take his son away. And it has happened, and it's going to continue to happen.

I've talked about this for probably four years now. One of the most disturbing responses I got from government was: When is the crisis date? I can only predict or guess when parents are going to die. I would hope that the flu shot works this year. I don't know what else to say. There are 400, and that was in 2003. So we're talking parents who are 51 and older. So I'm positive that those numbers have risen from the 400.

So what's going to happen if we don't have planning? Obviously, we can anticipate that there's going to be a growing number of aging parents. That 400 is going to increase, which puts strain on the disability support worker because then they have a crisis case. In most cases I'm the one that gets the call from the parent. So then I'm making sure that the DSP worker is making that an absolute priority for the day. So he or she's got the stress of me breathing down their neck, of trying to come up with a solution.

Unfortunately there's no beds, there's no plan in place. Some of the times I don't know the individual well enough because they've been isolated at home. So unless I live in that community or I know somebody who knows that person, there's a chance that

I don't even know who they are.

We only have a .7 full-time equivalent public guardian and she's already stretched to the limit with cases that she has. If we have 400 aging parents we're going to have to review the need of a full-time public guardian, because we do not have supported decision making in adult guardianship legislation. Now, I am aware that the adult guardianship legislation will be coming through. Unfortunately after almost 10 years of working on that, the supported decision making portion of that legislation has been significantly watered down, which is quite disturbing to many of us who have worked on that committee trying to get that piece of legislation in place.

Overall, all said and done, if we don't start looking at plans for these 400-plus you're going to see a huge over-spend in your DSP budget. Huge. Because you will be paying community care facility prices. It's just the way it is.

**Chair:** We are now, aren't we?

**Bridget Cairns:** Emergency respite care. People are going to say: If you want me to have them there in our house tomorrow, double the cost. Unfortunately you'll have no choice but to do that.

The next one. "Why can't I leave any money to my disabled son/daughter in my will?" Another reason why they don't want to do the planning. Currently right now I have a 13-year old, I have a full-time job, and I probably could, if like anybody else, put a few dollars away for my son. Unfortunately, with the policies that are in place, if I were to leave him any money DSP and other government services would say: Spend your mother's money first and then come see me. So that's a disincentive for me to do that.

I have a home. I'd like to leave my son my home. Whatever money I have in my

pension I'd love to leave for him. Unfortunately, it will just be absorbed the day I die. So there are disincentives. So there are families who are financially able to, and should be providing money to their son and daughter, whether they have a disability or not.

Similarly, I have a daughter. I will be leaving money to her. Actually, currently with the new policy, the policies on PEI, I will be leaving all of it to her. I would hope that I raised her well, but there's a chance she might not share that with her brother. I don't know what kind of person she's going to be when she grows up. I've no idea if she's going to marry the right man. So there's uncertainty. I'm wondering should I leave all my money to her.

Newfoundland and New Brunswick both have support trust legislation where families can leave money to their son and daughter without it making them ineligible for supports. Nova Scotia, I believe, is also pushing for this, with the assistance of Mount Saint Vincent and the Centre of Aging.

There's a way to help families and it's a neutral cost to government. It's a piece of legislation. This piece of legislation might actually save you dollars because there are families who can afford to provide but there's a disincentive to do that. So I highly recommend that you review this support trust legislation.

"Personal care is difficult for me. There is a provincial home care program, but they have a list of what they can and cannot do for us and the list is crazy. Home care workers can't do it but they want me to continue doing it." I try not to get too personal with this issue because it's one of those systems that just doesn't make sense. You either have to giggle at it or it just drives you nuts.

Personal care is not part of the DSP, so

when families need - we have an aging population caring for their son and daughter at home - to have a shower, if mom and dad are still doing it but they need some help, DSP says: It's not a service that we provide. So you have to go to home care. Home care will come maybe once or twice a week. Now, can you imagine not having a shower for the week, maybe once or twice? They have a list of: they can't bend, they can't lift, they can't stretch, they can't do - and it just flabbergasts me that the services that they need to provide, those activities of stretching, bending and lifting are required. Like, you can't just hose somebody down with a hose.

So a huge review of the home care program needs to be reviewed. Not only for people with disabilities, but for all aging populations.

Appropriate employment opportunities. I'm not sure if anybody drove through the Tim's this morning, but the individual there selling the papers - snow, any kind of weather, they're there. Most of them are receiving income support through the Financial Assistance Program. What money that they earn those days - and it's usually only about \$50 a month, if that - is deducted from their income support. So you wonder: Why in the hell are you standing out here when it's freezing cold if we're only going to deduct from your services? And they say: Because I want to work. They want to be a contributing citizen, but we still provide disincentives.

If there's an individual that lives in a group home and goes to a day program and makes money, the group home is obligated to report that income. So it's disincentives, and it's just one of those policies that need to be changed. I actually think that the people at Tim Horton's deserve a hell of a lot more money selling those papers out in the cold. So income support policies need to be reviewed.

I can leave you with what needs to happen. What I thought I'd provide you with - and I know I have enough copies here - is one day I sat down, and within the Disability Support Program polices and the Financial Assistance policies I identified the specific policy, and then underneath that described how it affects both our aging population and our families altogether. So I'll hand that out. This is ways that we can change the system. These are the systemic issues that need to be changed.

I also provided resolutions. I have them here. It does go past the aging population. It's basically the whole system. So just as an example of systems that affects families, we can go to page 4 of this document here, which is the Social Policy Reform paper, and it touches on housing. So say for myself, my son is now 18, which is not too - it's fast approaching. If he were to continue to live with me, if I continued to care for him - and it's not a financial issue, to make that clear - but in order for me to continue in the labour market, while still caring for him, the policies state that if my son continues to live with the parent, zero dollars would be given for room-and-board or shelter. If I were to give him to my sister-in-law, Ladine, she would get \$110. But if I were to put him in the Montague Manor, if I was to put him in the group home - no not the group home - the community care facilities - Sherwood Home or Hillsborough Hospital - that facility would receive at least \$417 a month.

So, where's the incentive for families or siblings to care for their family member? But yet this is what aging parents are still doing. With their fixed income they still say: I don't care if you don't give me any money, you can't put them in the institution. I think that's marvellous that families can do that, but it's also a shame that they have to live below the poverty line in order for their family member to continue to be cared for in an appropriate setting. It only shows where

the provincial policies are more supportive of institutional-like facilities rather than families first or family supportive.

So, yes, you can go through - I won't go through them all unless you'd like to - but if look this is the actual specific policy. So page 4 is the actual specific policy for the government, and then you'll see on page 5 our response to the policy. So I've addressed each specific policy in detail because I'm - I was at the point where I was tired of talking about it, I had to actually pinpoint where the problem was. So hopefully that's the information that you guys were looking for.

On page 7 it hits on the support trust legislation. Page 7 addresses the support trust legislation, which I mentioned earlier. A person cannot have more than \$900 a month in their account. So if I wanted to leave my son even \$1,000, that \$1,000 would be absorbed by the government the next day. So these are specific policies that need to become more family supportive.

The other paper is my resolutions, which is basically my bible. Hopefully this is helpful information, and I'm open to any and all questions.

**Chair:** Okay, are you ready?

**Bridget Cairns:** Sure, yes.

**Chair:** (Indistinct) we're kind of lining up here for questions.

**Bridget Cairns:** Yes.

**Chair:** So if you're ready then we'll start. Cynthia, Mike and Rob are the first three.

**Ms. Dunsford:** Bridget, of all of the families that we're talking about, is there any sense of a percentage - and maybe you all have this or can provide this information - of the percentage of families who would be requiring or want that support to keep the

kids at home and how many wouldn't?  
Because we know some do and some don't.

So what is that? Because the policy is written for, as you say, assuming that everybody wants to put their child away, let's say, instead of keeping them home. So are there any kind of stats that reflect that percentage?

**Bridget Cairns:** No official stats. I see a divide between the young and old. I would, in my guess, say that families that have experienced inclusive education, probably from grade eleven down, absolutely refuse any existing services, including group homes, because they've benefited from inclusive education and inclusive communities.

**Ms. Dunsford:** Right.

**Bridget Cairns:** The more aging population feel that need for support 24/7, and it's just the way that they were raised and the expectations of their caregivers. But there's nothing official.

**Ms. Dunsford:** Based on not so much the age - I know that's an important factor, as well - but based more on kind of the severity too, right?

**Bridget Cairns:** Yes.

**Ms. Dunsford:** And care level.

**Bridget Cairns:** I have a boy who is about to graduate from grade twelve but has always experienced inclusive ed. He's probably 9 to 10% of the population who have severe needs and the parents have grown up in a more inclusive setting. So, no, not even him.

**Ms. Dunsford:** Wow.

**Ethel Ellsworth:** In West Prince there's one family who have two daughters with severe

needs, both in wheelchairs, and they continue to care for them with what support they get. They're in the school system, or have been in the school system, and they are not looking for someone to take their daughters in. They're looking for the service in their home, to have (Indistinct), and I talked about long-term planning with them, and they would want something in place for their son and daughter to continue to remain in their home when they're no longer there.

So that is the difference, and I agree with Bridget.

**Ms. Dunsford:** Well, yeah, and that's to recognize too that the inclusive education piece is not just inclusive education, it's care. It's care.

**Ethel Ellsworth:** It's inclusive community, it's inclusive practices.

**Bridget Cairns:** And it's the evolution of human rights.

**Ms. Dunsford:** Exactly.

**Bridget Cairns:** Right? The younger generation have been educated that they have a fundamental right to live in the community. It's the evolution of that, as well.

**Chair:** Okay. Mike, you're on.

**Mr. M. Currie:** I'm interested, Bridget, in the assets in regards if you left your son a sum of money. In the other provinces, is that an enhanced level of service, that if you left them x amount of dollars it should do them for 20 years? Is that what it does? Like, he stays where he's at, but he has an enhanced level of service?

**Bridget Cairns:** Yes. Like, Newfoundland has support trust legislation where families are entitled to leave up to \$100,000 in trust to their disabled son or daughter. That

money is used for - say I left Joey my home on the County Line Road. If that money - see, government won't pay for roof repair, furnace repair, certain things for independent living. That money could then be used to sustain the home.

I currently can leave him my home. I know that there's one individual in your area that is a homeowner. If that home ever had to be sold, that would be considered liquid assets and his DSP would be cut off. So that's a scary situation to be in and some planning will need to be around that. So I don't want to leave him my home in case he needs to downsize or wants to move. All of those years of paying my mortgage will be gone the minute I die. It would be used for stuff like that.

The financial assistance program will pay for a certain amount of prescriptions or dentures, clothing. I think clothing is, what?, \$60 a month. Unfortunately, you can't buy very much for \$60. That's why years ago we saw individuals wearing the polyester pants and the very hand-me-down clothes. I'd like to leave him some money so that he can have some sort of collection of clothing. Not saying he needs the leather jacket, you know, every year, but for clothing.

**Mr. M. Currie:** Legislation has to be changed to adapt that. That's what this is.

**Bridget Cairns:** Yeah. And it's an absolute neutral cost to government.

**Mr. M. Currie:** Okay.

**Bridget Cairns:** It will actually save you guys money.

**Chair:** Just a quick question. Did you say New Brunswick and Newfoundland?

**Bridget Cairns:** Yes.

**Chair:** Okay, Thank you.

All right. You're done, Mike?

**Mr. M. Currie:** Yes.

**Chair:** Okay. Rob Henderson, I think, and then Paula.

**Mr. Henderson:** Yes, I thank you for this presentation as well. It's very thorough. As an MLA it sort of gives us some realistic options here or whatever.

But as an MLA, all of those issues that you've brought up, I've encountered every one of them as an MLA, from the clawback to the DSP, to the working wage, to inheritances and all that type of thing. So it really does sort of hit home there. It just astounded me, as an MLA, when I started taking in this. I can't believe that. You just get a little bit of money and all of a sudden you lost everything else. They didn't get anything.

**Bridget Cairns:** Yes.

**Mr. Henderson:** It was amazing. But I think the other thing, when it comes from the residential component of the thing, is that residents even within their own community - like somebody that, say, has a problem and they're living in, say, Tyne Valley, to put them into a facility in Tignish that they have no sense of familiarity, they have no idea where it is that they're going - so there really has to be some sense of familiarity with their housing needs in centres and things like that.

**Bridget Cairns:** Yes.

**Mr. Henderson:** We all have our unique communities or whatever, but I think that's something that's probably (Indistinct). So anyway, that's more of a comment, I guess, to thank you for the presentation and those issues.

**Bridget Cairns:** It's evolved from this

because I'm so tired of talking issues. I think the only way to logistically, or the only way to logically explain it is, society has evolved but our provincial policies have not. They need to be updated.

**Mr. Henderson:** I couldn't believe it. I had a lady, (Indistinct), she's, like, I think about 80 years old and partly blind, and she had daughter - or a granddaughter I guess it was - that she's been looking after all her life, and the fact that home care and support can only come in for a certain time, and this girl needed to be bathed and showered, whatever, and Depends on and stuff like that, and they couldn't do it. I couldn't believe that.

**Bridget Cairns:** That's what I'm saying, so

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**Chair:** Happens all the time.

**Bridget Cairns:** Yes. That one just makes me chuckle. I just have to scratch my head.

**Mr. Henderson:** It was a heart-wrenching story and I couldn't believe that there was nothing there, through home care support or DSP or anything, to help that particular situation. But yet that family is struggling to keep that person at home versus in an institution. Anyway.

**Chair:** Paula.

**Ms. Biggar:** Bridget, in terms of you're a young mother with having put your son through the inclusive education system, and now you're in a transition phase, from your perspective, what systems need to be in place for transition there? I'd like to get your opinion on that.

**Bridget Cairns:** Through a project that we had funding for, we just finished developing a new transition model that's is being implemented across the province. Unfortunately, the choices are not out there.

My son, I'm just beginning his transition plan, and we're working on what to do in emergencies and how to do basic life skills, like cook, clean, and stuff like that. The next step will be looking for employment. There's very little employment in our area. The first question was: Where will he live? I don't know yet, because it's going to be with me, because that's all there is. I can put him on a wait list for the group home or I can create more services, but I'd have to create it myself.

So what it is is the options in your community. Right now, if I had no other choice but to make a plan on existing services, I would have to migrate to Charlottetown and leave my community.

**Chair:** Anyone else with any questions for Bridget?

**Mr. M. Currie:** Is Judy Misener associated with your program too? Do you know?

**Bridget Cairns:** The name's not familiar, but if you see me talking to her tomorrow then don't ever tell her that I forgot.

**Chair:** Any other questions?

**Bridget Cairns:** If I could just state one thing. Because it's a systemic issue, it's not that we can just address aging population. It's the entire system.

We don't have an early intervention strategy on the Island. We have pockets of services but we do not have a system, which is going to affect our leadership, that we are nationally recognized for in inclusive ed. Because what's happening is these kids are not being diagnosed, and when they are diagnosed they're put on a wait list. They're entering the school system with no supports because then they're aged out, they're age six.

We are going to lose our national

recognition for inclusive ed, which is just going to domino everything else. We really need to make disability a priority for the province or we're just going to landslide right down.

**Chair:** No more questions or comments?

I thank you, Bridget.

**Bridget Cairns:** Thank you.

**Chair:** That was certainly very informative.

**Some Hon. Members:** Hear, hear!

**Chair:** I'm sure you're aware that the Department of Health, disabilities and supports, are all going to be reviewed across the province.

**Bridget Cairns:** I'm actually chairing a few of them.

**Chair:** Yes. So anyway, there's certainly a lot of good information that you've brought forward here and the committee is certainly committed to put forth a good recommendation in the spring.

Okay, somebody else is back there waving.

**Mabel Thompson:** Excuse me, I'm just wondering if I could speak for a moment?

**Chair:** You certainly can.

**Bridget Cairns:** Come up here, Mabel. My chair's nice and warm.

**Chair:** Come right up. I'd like you to introduce yourself, too, before you start, Mabel.

**Mabel Thompson:** Okay. We're Jim and Mabel Thompson. We're parents of a handicapped son. We're here to tell you first hand that we're aging parents caring for a challenged son. Our son is 36 years old. We

have supported and encouraged him all through the school system, but not without resistance.

He was very involved in Special Olympics, travelled to several places for competitions, and became independent and proud of his accomplishments. Nine years ago he decided to leave home and move into a group home where he would be more independent. After three years he moved into it with an associate family and during this time he worked at Canadian Tire and could never be more proud of himself.

A little over two years ago he had a lung condition and it worsened, and he has now got chronic lung disease and only has 25% lung capacity. Because there was no facility at that time other than a nursing home to put him in, we had no other choice but to bring him back home.

We have now become his caregivers, and because we are his parents he has now, somehow, become our responsibility. What other parents do you know that have to be responsible for their 36-year-old son? If we want to go away for a holiday, we have to save our monthly respite allowance up for several months and accumulate it in order to go away for a period of time, which results in maybe five to six months of no break away from our son.

While our son was living away from home financial assistance was not an issue, but now that he is back home we are considered to be financially responsible. There's money available through the Disability Support Program but because he lives at home we have only access to a small portion of it.

In closing, we want to know what government is going to do to correct this issue. There are many parents in our situation and we feel things need to change or government will be responsible for us all. Because they're just going to burn us out.

We need help. Because he lives at home they don't want to give us any assistance. He's getting better care, he's happier, he's in his own community, and whatever. So I thank you.

**Bridget Cairns:** Very good. Good job.

**Chair:** Thank you.

I guess we'll move for adjournment.

**Mr. Bagnall:** So moved.

**Committee Clerk:** (Indistinct).

**Ms. Biggar:** Melissa, how are we getting along with confirmation of the oil representatives coming in?

**Chair:** Just one second.

**Committee Clerk:** Well, they had asked that I call them at the beginning of February regarding the February 5<sup>th</sup> and 12<sup>th</sup> meetings, so I was going to call them next week to touch base with them. They knew about this meeting and last week's and couldn't come for sure.

**Ms. Biggar:** Did Faye Martin get in touch with you?

**Committee Clerk:** Yes, she did. She's coming in on the 12<sup>th</sup> instead.

**Ms. Biggar:** I think she has to change that again.

**Committee Clerk:** Oh. Okay, that's the last I had heard. She needed (Indistinct)

**Ms. Biggar:** I saw her this morning.

**Committee Clerk:** Okay.

**Mr. M. Currie:** Are we adjourned?

**Chair:** No, we're not adjourned.

**Mr. M. Currie:** Oh.

**Chair:** I just have one other thing I just wanted to ask you about before we left.

We did have a letter come in from an organization that would like to come in and present to the committee. Of course, I'm sure everybody would be - it's the Society of St. Vincent de Paul, Holy Redeemer Conference. Veronica Grandy is the president of that organization.

**Mr. Bagnall:** Sure. We have no problem with that.

**Ms. Biggar:** Surrounding oil, cost of oil.

**Chair:** Yeah, cost of oil. I guess the other thing, too - they think we're adjourned here.

**Mr. Bagnall:** Keep going. We can hear.

**Ms. Biggar:** We can hear.

**Chair:** Okay. There has been some question about whether or not we're going to have some public hearings in regards to the fuel costs. Do people at this time feel that it's something that we need to consider or do we want to continue?

**Ms. Biggar:** This is open. It is open for them to come and sit here.

**Chair:** Yes, it is.

**Mr. M. Currie:** I'll move a motion that we have rebates. It was promised. I'll bring that next week.

**Ms. Biggar:** We'll be ready.

**Mr. M. Currie:** Be ready.

**Mr. Bagnall:** You'll have to withdraw that, Mike.

**Mr. M. Currie:** I have to withdraw it?



**Chair:** The majority of us are certainly -

**Mr. M. Currie:** Oh, well, you'll support me. Thank you.

**Chair:** No, no, no.

**Ms. Biggar:** Aware of the request.

**Mr. M. Currie:** I'll go right to the media now and tell them: Chairman supports me.

**Chair:** No, definitely no.

**Ms. Biggar:** There's been no vote on that.

**Chair:** Thank you.

**Committee Clerk:** Motion to adjourn?

**Chair:** Motion to adjourn, yes.

**Mr. Bagnall:** Adjourned.

The Committee adjourned