Transcription of Don Mullins - Our Voices Matter Interview

Interviewer: Anna Quon

AQ- This is the Our Voices Matter project, I'm here with Donald Mullins, Don Mullins, umm who I am going to interview, my name is Anna Quon, the date is September 22, 2010. And we're here at the Belmont House in Dartmouth.

AQ- Hi Don.

DM- Hi, how are you, nice to meet you

AQ- I'm fine thank you and you?

DM-I'm fine

AQ- So can you tell me a little bit about your childhood, where you were born

DM- I was born in Halifax Nova Scotia,

AQ- Yup and umm where, ah when were you born?

DM- At January 1st 1951

AQ- January 1st?

 $\mathbf{DM}\text{-}\ I$ mean January 18^{th}

AQ- January 18th, ok. And umm what was it like growing up in your family

DM- Challenging

AQ- Mmhm

DM- My family consists of eleven different children. Ah I'm a twin, identical twin. Which presented some problems. Ah back in the early years just after the war there were different averages than there is today, by far. Ah mental illness wasn't understood at all. Umm and having a disability on top of that right, and I had a father who was lack of a better word was a bigot. He was an abuser, and ah, he didn't want his neighbours to know he had a disabled child. And the first word out of his mouth to my mother was that NO disabled child of mine is gonna live under my roof. So for many years they kept me hid away. And but it's hard to say I never went to school, I was considered retarded. But my main illness, my main health issue is cerebral palsy. Which also wasn't understood but it was recognised. Umm from there it was very difficult to live with a twin, who you couldn't socialize with, the only time I was allowed outside was when the kids were in school, I used to play under the front steps and pretend I was in school. And I didn't have any friends because he didn't want anybody to know he had a child such as that. Then I hid up in the attic and stayed up there. When I say attic I don't mean just an attic per say it had a bed in it and it had steps going up through it but there wasn't much comfort. Ah this is very difficult for a child to see all there brothers and sisters have a life and stuff, it changed when I got into the Nova Scotia Hospital many years later. But not, nobody knew about it. Umm they did become aware of it at some stage of the game, I think when I was 6 or 7 then I went to be reassess and was labelled retarded. Not, I wasn't, they said I was never trained to do anything; I could never have the capability to, cause he didn't understand a lot of things back then, and so because of that, that nobody really wanted to do anything. It was ok to sit home. Ah, umm, I got depressed, a big chip in my shoulder, umm felt very much suicidal, and in the end I ended up in the Nova Scotia Hospital for taking, for trying to commit suicide too much.

AQ- How old were you then?

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DM- I would be I am guessing, I am not good with dates, but I would say 7

AQ- Seven! You're first suicide attempt?

DM- I believe so, yeah.

AQ- And were you, were you hospitalized after that attempt?

DM- Not for many times, my family kept it quiet. But when I was older and I mean 16, ah I went and tried to jump off the ferry. That became public. And ah, from there I went to the Nova Scotia Hospital. And I remained there for at least a year. They didn't give me any drugs, there treatment for me was to put me in N13 which, which was a behavioural ward, and to talk to me every day, a specific person, and then we would just talk like you and I are talking. And learning to be me, finding out who I was. So they'd come back and I would ask questions, the whole process, to gain confidence, understanding, and, and it worked really well. But my family couldn't come visit me. Everybody, nobody was allowed to see me. If I wanted to go to my sisters party, ah I

AQ- Oh.

DM- But that, that was a long, a long time.

AQ- So the N13 was at the Nova Scotia Hospital

had, I had to earn so many points in order to go there.

DM- Yes, yes it was.

AQ- Ok, umm, so were you, so you weren't put on any medication while you were in hospital?

DM- No they, they felt it was more understanding my feelings and trying to bring me into the mainstream of living.

AQ- Right,

DM- Cause I lacked that skill

AQ- Right, and that was at age 16?

DM- Age 16. These are approximate ages, right.

AQ-Ok, sure

DM- Because I, I've blocked it out. So that's how I can do what I do today. Out of that came caring for other people, and the work I do today, in lots of ways, right.

AQ- Right, so umm, did you have any inkling of your mental health problem before this happened. Like how did you...

DM- That just compounded things, because my father was such, attitude wise he didn't even want to hear about it, you know they weren't allowed to talk about it and my brothers and sisters would say "Where's Donny?" and they'd make up stories. And pretend right.

AQ- OK, yeah, so when you were in the hospital for that year and a half and you were discharged where did you go?

DM- Umm I went to a, what they call a group home on Walnut Street and I was there for about another year. And when I, when I went to leave when I could go out on my own to see how I do,

umm there was a friend I met there who I, who today I live with. So my life has been pretty straight forward in that sense.

AQ- Right and is that your friend Eric?

DM- Eric, when, when we decided to leave when it was our time we agreed to look out for each other, and always there for each other. No conditions. And we stuck by those principals.

AQ- Ok, so umm, was it a positive experience being in the, or a negative experience being in the group home?

DM- Ah back then group homes where new, umm I think, I found it positive, I'm sure there were a lot who didn't. Cause they wanted to be home with their families. But I had no home to go home to per say. I found it positive.

AQ- Maybe I can go back to your time in the hospital, umm it sounds like you had fairly regular contact with staff that was talking to you.

DM- Yes, yes

AQ- Umm what was it like in hospital for you for that year and a half?

DM- Ah, umm, prior to that year and a half, umm there was a series of being treated, released, treated, released, so I kept doing what I was doing and in the end how I got in N13 long term was that the doctor said "either your gonna umm stay here and go out positive or you're going to end up in Cole Harbour" So I chose to stay there, and that's how they really started taking me serious. That was my last and only time in the Nova Scotia Hospital; I was never in hospital since.

AQ- Oh, wow, alright, and umm and you mentioned your brothers and sisters wondering where you were, did you, what was your relationship like with your brothers and sisters and your mother?

DM- My mother, we were close but she, if, if, is she upsets the apple cart, if everyone didn't follow what he said then they umm, they, they wore the brunt too right. So that got to be one of the sore points we really tried to keep it, I tried, I had a sister that was in a fire, several disabilities right, and he, but he didn't see it as disabilities as fire or asthma or those kinds of things right. You, you could tell I had a disability cause I, the way I walked and stuff right.

AQ- Right umm so after you got out of the hospital and you went to the group home and umm how long was it that you were there?

DM- About a year

AQ- A year, ok then after that when you left the group home can you tell more about that?

DM- We took, we got our, me, me and my friend got a room and then we basically umm lived there about by Canadian Tire on Kemptville Road, umm for awhile and then we moved from apartment to apartment and stuff and we were pretty stable often stayed ten years or so in one place, ah I did work some quite a bit and I did ok, but umm it's, it's a everyday challenge dealing with, umm like I wouldn't answer a phone, I didn't know what a phone was, I, I never been part of that life right. You know it's different.

AQ- Yeah, you, you never knew what a phone was

DM- No

AQ- Wow

DM- Well because they knew but my father when they come home from school he would rush me right up stairs.

AQ- Right, ok, umm have you like since you where in the hospital that time and then the group home have you ever suffered from depression again or

DM- Ah they put me on this medication I think its speed but I don't know what it is but it gives me energy but it also takes away the depression but I don't think I have real depression. Yes I have suffered from depression since then that's why I take the pills all the time right. The last time I was in the hospital at Nova Scotia Hospital at nine in the morning by ten that night I had gone the whole system back at the hospital.

AQ- Ok, right, umm so living while your living in the community umm since that first time in the hospital and the group home have there been any supports that have made a big difference to you?

DM- Ah my supports are largely that they don't know my past they just see me as now. I've, I've only told three people and my father moved to Ontario the day after he turned 65, took the whole family but he said you're staying here. Ah, so the only person I have here now is that is family is my sister Joan

AQ- Ok, so, umm, and do you have other supports that are not family

DM- Umm, I have Connections, I have, I used to go to Caring and Sharing a lot. That, they, were a good support.

AQ- Ok, and when you say Connections do you mean Connections Clubhouse?

DM- Yes I do

AQ- Ok, and umm have you ever experienced umm emergency help, like soup kitchens, food banks, shelters, police lock-up, mobile crisis unit

DM- I know about them because of my job but I've never been a client. I've gone Turning Point and stayed overnight to work with people, to talk to people at night time.

AQ- Ok, right umm can you tell me about your work?

DM- My work ah, is abo, is about helping people fac, like face to face. And sometimes it requires listening, sometimes it requires help with housing, whatever their need is regardless if there a member or not as long as they live in HRM, I do take people outside of HRM occasionally. I, I, I try and work to help give them confidence and build beyond the stumbling blocks

AQ- Right, ok and umm is that paid work or volunteer work

DM- No it's all volunteer

AQ- All volunteer, umm and you had other kinds of jobs as well.

DM- Ok, I worked at the YMCA, and became supervisor I worked there a long time, about five years.

AQ-Ok

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DM- I worked at Housing became involved with the union quiet a lot for about another ten years.

Ah, once I let my past go and decided to go forward and really build on that. Ah you know they

said I was retarded and all that, I felt I could manage and I feel I have

AQ- Ok, how, what was this certain kind turning point that made you realize that you could have

a life.

DM- Well I had that whole year in the hospital

AQ- Yeah

DM- With no real family just positive imputes. Right, and the reason they put me in N13 was so

that I could appreciate how life could be for people.

AQ- Right

DM- That was the message, right.

AQ- Yeah

DM- You could, you could be one of these people. N13 was rather a, a, a floor of people who

were just lost. You couldn't communicate with them very well. They varied but they were

mostly to say these people don't have a life either and there managing but not much of a life, you

have a change to build on yours.

AQ- Right, right, were, were you told that exclusively

DM- Yes

AQ- Right, ok, umm so what I know I am jumping all over the place but when you where in hospital umm among people who umm as you say where lost umm did you make any long term connections with those people or

DM- Ah, ah, I'm friendly you know my personality I am sure I made contact but they were there for a long time too. It's a long term floor. Umm there were some individuals that were similar to me in some ways so yes I made some contacts

AQ- Ok, umm what about your spiritual life, what do you have, is that an important part of your life

DM- It is but I used to go to church, my mother is a Joho witness and that created a lot of problems. Umm so I, I, I prayed a lot and I still pray a lot and I actually sometimes when I lived in Timberlea I would walk the railroad crossing, I wasn't good at making friends, I lacked the skills for comfort, right. Umm so I would think out loud, particularly on the train tracks just quiet, nobody around. I could just voice my opinion not holler and screech just think out loud. And get perspective so and I believe and I do it all the time that you can talk to god or, or, say prayers at any point he hears you wherever your at.

AQ- Right

DM- I've gone to churches umm they've been positive ah, but I haven't gone on a regular basis.

AQ- Ok, umm how would you characterize your personal life right now is it good, bad, helpful, lacking, what kind of words would you use?

DM- I, I would say I've, I've done quite well. My person that stays with me ah, ah were very close friends. He's a challenge with help and I am very fortunate.

AQ- Ok, umm what kind of challenges have you faced and do you still face living in community?

DM- Ah, my biggest challenge in the community is the understanding of the disabled. We, we still have ways to go. You, I say most people see people on a chair or some other type of disability and think good about it. But you don't feel the pity. The pity goes with "oh that poor, that poor boy".

AQ- Right, right, umm do you have any leisure activities like hobbies or things that you enjoy doing that help you stay well.

DM- Oh I may mostly, mostly I watch certain shows, and stuff that I appreciate. But, but what makes me stable is the challenge, the challenge and wrath of other people and to see the difference it can make if you can support them.

AQ- Right, ok

DM- That's very self-rewarding

AQ- Mmm, mmm, have you, have you experienced discrimination due to your mental illness ever

DM- Yes, umm, yeah I been robbed a couple of times and the reason is because of what they think of people. Umm yes my way of dealing with those kinds of things is to think a simple thing that, "that's there issue not mine" I mean they don't know me they just judge you, right

AQ- Right. So when you say that you umm, were robbed and it was because of your mental

illness was it when you weren't doing so well or when, like how did it sort of happen

DM- A combination of things that largely but due to the fact that, that I tried to be somebody

nice and I got used and they told their friends then they set me up and robbed me.

AQ- Oh ok umm and do you experience poverty, like how, can I ask where your income

DM- My income is 6, 637 dollars a month

AQ- Oh not the amount but just where you get it

DM- Canada Pension

AQ- Canada Pension ok

DM- Disability

AQ-Ok, ok

DM- I also live in housing so my rent is not that much.

AQ-Ok, ok, ah, that's good to know. So have you found that housing a support important to

your well being?

DM- Well I used to live in ... for many years and I worked in the Macdonald building so I was

very hesitant to go into housing but the answer I would say is yes, cause without making those

changes in the early days, I'd probably be on the streets today I could never afford the rents.

AQ- Right, right. K, umm have you, you said you worked in several places and the place that

you volunteer right now is called DIAL

DM- Disabled Individuals Alliance

AQ- Ok and am I right in saying that you do advocacy work there

DM- That that is our biggest part another we have is a social program sort of for the

members.

AQ- Ok what kind of social programs

DM- Swimming, ah we have Christmas dinners; ah we have men's night, woman's night, ah lots

of activities right.

AQ-Ok

DM- We, I believe that you can't be well unless you have a balance of both.

AQ- Right, ok, and what about your family have you, are you in contact with them.

DM- Oh yeah my father passed away and my mother died a few years before that, so now the

whole family is ah, more like a family. I talked to my brother last night, he drives a truck all over

the states but yeah we're much closer.

AQ- Right, umm you, you'd said you were one of identical twins

DM- Yes

AQ- Does your, did your twin brother have any disabilities

DM- Yeah, he, he had a speech problem, and he couldn't read very well.

AQ- Ok, ok, umm and how, like does, does your family feel the same way about you as your father treated you

DM- Yes

AQ- Or have attitude towards you

DM- Yeah well he's also abused my sister sexually and other things that are now coming out umm we didn't know this but as, as are sisters are getting older and stuff there is a lot of resentment towards my father.

AQ- Right

DM- All the way around

AQ- Ok, umm when, when you were young and you were first attempting suicide umm what were you thinking about at that time

DM- Loneliness and being different, and not knowing, not knowing why.

AQ- Right umm, and is that like, do you blame your father for those feelings you experienced

DM- It wasn't just his attitude it was his ego. Very much so. The day my mother died, she had moved to Ontario she, she was in a hospital there and my father had been retired when he moved up there so then he found, I call a girlfriend and he was standing outside with his new girlfriend and he knew his wife was two floors up.

AQ- Oh ok

DM- She saw that.

AQ-Oh,

DM- So he wasn't a nice person.

AQ- No, umm so ok, you told me about an important relationship in your life with your friend Eric, do you have other important relationships in, in your community that help you.

DM- Many, I have many people umm people I work with umm different groups belong too, I'm rich very much.

AQ- Ok umm is there anything you would change if you could go back in your life and do something different

DM- If, if, if I knew what I knew now then I would be more assertive

AQ- More assertive, ok, umm so do you consider yourself as a person living with a mental illness now

DM- Yes

AQ- Yes, ok, and you take medication you mentioned

DM- Yes, I take a lot of medication.

AQ-Ok

DM- That keeps me well.

AQ- Right, ok, umm and it sounds like the quality of your life with the mental illness has changed over time

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would consider normal but umm there just once you understand something, my ill, my illness

DM- I understand it better and, and I know, I know I need plenty of rest at, like, what most

cerebral palsy is now starting to change like we all thought it would never change, right. Back in

the old days they used, for what you have now is what you'll have all your life, most people

turning my age in the first group experienced a lot of number of things, right.

AQ- Yeah

DM- So, its understanding enough to know what's good and bad.

AQ- Right, ok, and so, ah, you have umm you live with cerebral palsy and you also live with a

mental illness umm how do you think the, those two things together umm affect your quality life

DM- Ah, I think, I defiantly think the cerebral palsy is going to put me in a chair taking away my

freedom to independently walk largely that's one thing is that, and the mental illness affects my

good days and bad days. My days are becoming now days where I can't just go, I have to, to rest

and do things to stay well

AQ- Right

DM- I never had that to this degree before.

AQ-Ok

DM- And now its common out of a month there's ten days I can't move

AQ- Alright and that's due to the mental illness

DM- Well yeah

AQ- Or both

DM- I am starting to feel, experience a lot, a bit more depression and stuff because I am scared

of what, what's going to come next

AQ- Oh, ok, and when you say you are scared of what's coming next is that to do with aging

with disability

DM- That's part of it but the bigger part is when you've been told things for years and all of a

sudden you're being told, being told that that's, we don't know, know what to expect from here.

I've talked to many people with this kind of illness and there in the same boat, it doesn't make

you feel very comfortable

AQ- Right

DM- Secure

AQ- When you say ah, talking about your illness umm and you don't know where you'll go from

there is that the cerebral palsy you're talking about

DM- Umm the cerebral palsy I think I can manage but having the two together may at some

point I believe will put me in nursing care.

AQ- Ok have you found umm that your physical disability has had a lot affect on your mental

health umm in ways for example like if something or if there were places that were inaccessible

like mental health clinics that were inaccessible or doctors' offices

DM- A lot

AQ- Yeah

DM- A lot but it's better, we've come a long way in the last fifteen years

AQ- Right

DM- Ah but we still have a long ways to go. Connections is a fine example umm I have to do everything, everything I do now has to be on the first floor so if they have something on the second floor I'm unable to attend.

AQ- Right

DM- Ah, at Caring and Sharing I wasn't in a wheelchair but a lot of people were going back to Caring and Sharing through the changes ah it is the smallest space so I would be in the way there

AQ-Oh

DM- Cause the Caring and Sharing club itself is not that big. And with all these new members coming in I would be in there way.

AQ-Oh

DM- So I am victimized once again.

AQ- Do you, is that something you've been told or is that your own personal feeling of it or

DM- Well, I was there ten years before when they were up in the other space I was walking.

Now that I am not walking I've been there and I'm going there next week for the party for what's his name. Ah but on a regular basis my common sense tells me it's full of people especial

on meal night or something big would be a real challenge. They are looking for new space, I hope they get it; I am waiting for that to happen

AQ- Right, ok, umm aging with a physical disability and a mental illness it, do you see that as having a double whammy kind of thing or

DM- Yeah

AQ- Yeah

DM- But I've created a positive attitude approach to life and that two tier, one tier is I always get my work and I think it makes a difference it makes me feel better and helps me understand them and me. Second tier is I can't change I have to only accept or find ways to work with whatever comes my way. And, and that's my core belief. So it doesn't get the better of me

AQ- Right, how does helping other people for example through DIAL how does that help out and how, how does that affect your mental health

DM- Well it ah, in two ways again I see but, but how life can affect all ages and how bad it can really be, umm its, it's a good feeling the giving of yourself but its knowledge or support or whatever it is you give but you get back more than you could give. I am only giving time and knowledge, there, their feelings they give back in return, just where there coming from is so rewarding.

AQ- Right, right umm do you have a mental health professional who see's you now

DM- I, I, I used to see Doctor MacDonald, psychiatrist umm but they; they discharged him because of a personal issue with a patient. But I had, I've gone to Demolton at the Abi Lane for a long time. And he's now changed so I am in the mist of looking for somebody to take his place.

AQ-Ok

DM- And that's a challenge now of days with all the cutbacks.

AQ- Right, right, and how does that affect you not having a therapist currently

DM- Ah it, it makes the days that are bad that much worst cause you can't pick up a phone and say do I need a medication change or not. I, I have a family doctor that I have been going to for a long time and he's pretty good ah

AQ- Yeah

DM- But I'm falling through the cracks in that respect

AQ- Ok, what do you think could help you in that situation by are there any other resources you can go to get help for like finding a therapist or

DM- Oh my name is on what they call a list at the Abi Lane umm but, but there's situation, there's need for doctors of all types that I've asked not to be, if there's somebody who needs it more always put them first.

AQ- I see

DM- Cause I'm, I'm managing, I've haven't been in hospital I do actually pretty well everyday so to speak, right.

AQ- Right

DM- Like I, like I now have bowel problems that have now become real issues and stuff, but I am still getting through the day, as you talk to me you can see I have a strong positive attitude and I have a quality of life. There are people out there that, that; special needs people that need the doctors, right

AQ- Right, ok, looking back on your life umm what are, what are some of the changes that you see in the mental health system from the time when you first had contact it

DM- I see that it has grown a lot

AQ- The mental health system has grown or people, more people with mental illnesses

DM- More people, demands on the system.

AQ- More demands

DM- I see how the health system trying to provide but there's no where nears funding, the funding or the support for staff, people having to wait longer and umm with some tragic results.

AQ- Yeah

DM- Umm people are finding, its biggest task I think we all have is to get the government to listen to us in a serious way and to build a long range plan.

AQ- Right, ok, are involved with any mental health related organizations like besides as a, umm member or client social clubs, are there any mental health organizations where you

DM- Ah, umm I, I, I talk to CMHA a lot, Marg Murray and a few others, I support them and we, we meet at many meetings, we cross paths

AQ- Right

DM- Ah she knows my belief on understanding the need, supporting ah

AQ- Right

DM- I talk to (Name)(34:11) several occasions about what I see out there

AQ- Right

DM- And stuff

AQ- When you look back on your life are there any particular people in your life you mentioned Eric, your friend Eric are there other people like health care professionals or, or supportive people that stand out for you

DM- Umm in counting me, yeah there are. Umm Susan Hare has been a huge impression on me she's helped me a lot, so has Gale Kelly

AQ- Ok and where do they work

DM- Well now, well they were at Connections

AQ-Ok

DM- But Susan Hare now is over, over at **CMHA** right by the Abi Lane

AQ-Ok

DM- She's a very informed person and very caring. And I often talk to her, and a lot of nurses at ... I get very personally close with.

AQ- Ok, now umm do you do any umm any spiritual practises, I know you said you believed in god but do you do any umm any exercises or meditation or that kind of thing to stay well.

DM- I do acupuncture

AQ- Acupuncture, ok, and where do you get your acupuncture done

DM- Through Connections, we go up to the church to do it.

AQ- Ok and how does that help

DM- It relaxes me. I don't, you know, particularly it helps me keep calm

AQ- Right, ok, so umm and let's see, umm have, I, I know you've said you experienced discrimination due to your mental illness umm has that changed over time, have you seen a change in the way your treated

DM- Oh definitely, both as a mental health and as well as being disabled and in a chair. There, there in large part is from acceptance and tolerance, ah understanding

AQ- Right, right, ok, umm has any of the more recent in developments for example involuntary psychiatric treatment act or the mental health commission of Canada have they impacted your life in any way

DM- No they, I have never had to be in hospital

AQ- Right, ok umm how would you describe yourself like mental health consumer is one word is that a word you would talk about yourself?

DM- If I met a stranger, how would I describe myself is that what you are saying

AQ- Umm yeah sure

DM- Umm I am a consumer,

AQ- Consumer

DM- I find that it's a less tension of a word and its more understanding about, about the community.

AQ- Right, ok, umm and what do you find now helps you get through a difficult time

DM- If it's a real bad time to umm go next door and just umm lay back and think a bunch of, you know it's bad when my mother was there and I can think what she's taught me, what I stood for and, and that makes me feel closer, I'll always feel close to my mother but I think she understands about how I feel and through that I get through it

AQ- Right, ok, umm I guess my ah my final question would be what advice do you have for umm friends, family, mental health practitioners, on how to help a person experiencing mental illness

DM- Is the, is the question what's my, what, what...

AQ- What advice you would give them people that want to help

DM- Patience and understanding

AQ- Patience and understanding, ok, ok is there anything else you would like to add Donald too

DM- I, I think the doctors are more trained and better understood these days but there's, they

need to understand there qu, qu, quiet, people with mental illness that don't follow the norm.

And those people, that's the people they need to understand and stick with them and work, go

down the path together

AQ- Right and when you say don't follow the norm do you mean someone who has a duel

diagnosis or

DM- Yeah normally when you have schizophrenia you act within a boundary in a certain way,

but there are some people who have that illness who don't they just may the symptoms but

follow, doesn't work for them you just stick with them longer and more hands on

AQ- Ok and what, what would be your sort of words about living with both a physical and a

mental disability like what would your advice be to people

DM- Umm teach them, work with them to become their own person give them lots of support in

all forms and be patient

AQ-Ok

DM- They may, you may take x number of months to get to a certain point some people may

take far more

AQ- Right

DM- We shouldn't just let them go right

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AQ- Ok and what else is there anything you'd like to add to your story umm

DM- Umm I think for my day right were all called dysfunctional families and I think there a good many of them in one way or another like I not a person that can touch another person I wont let anybody hug me or get that close to my body and that's because I've never experienced

love in that sense

AQ- Right

DM- And, and

AQ- Ok

DM- It's, it's a part of life it was tough times, today's world they've come along way

AQ- Thank You

DM- Thank You