

March 10, 1998

Marge Hankey
Ministry of Children & Families
Box 1860
Summerland, B.C. V0H 1Z0

Dear Marge:

I am really sorry that the team meeting on March 6, 1998 had to be cancelled but the flu hit us here like a two-ton truck. Being so ill, also reminded me of how very much work Jeremy is and the reason we need respite not daycare.

I just want to go over our telephone conversation of Wednesday, March 4, 1998. At that time, you said that your supervisor stated that indeed Jeremy did need a more intense program. So I was offered daycare with a one-on-one aide, five mornings a week for Jeremy. You said that Steve (Liddiatt) would oversee behavioral management. When I asked if this one-on-one aid could take our 3-day workshop we are planning to put on, you said that Steve (Liddiatt) said that "She would have to go as a volunteer because if she got paid then it would look like the government was endorsing Lovaas-type ABA and with a lawsuit coming up, they couldn't do that." Let me say, that I know of no lawsuit, I am not involved in a lawsuit with the Government at this time, so why is my child being discriminated against **again** over hearsay?

Now onto my second point, daycare is not an option for Jeremy at this time. I see no reason to pull him out of his preschool which he really enjoys, has settled into, with a one-on-one aid who he is comfortable with. Also daycare is not a place where Jeremy would do well. I will state again, that autistic children do not learn from imitation or their environment or by watching others. We could put Jeremy in a daycare for seven days a week, ten hours a day and he would still not learn. Jeremy needs to learn how to learn. At this time, while he needs the socialization, I feel this is met through his preschool days and is adequate at this time. What Jeremy needs moreso right now is one-on-one attention to address his many delays, this would be best met with in-home daycare. Thus do I not only feel that daycare would not be beneficial to Jeremy at this time, I feel it would be detrimental to his already delayed progress.

Let me go over again just two of the reasons that I feel the Lovaas-type applied behavior analysis will work. One of their first objectives is to make eye contact. While it was mentioned that we needed to do this with Jeremy, no one had any ideas that worked. Well, the ABA info did. With one week of very hard work, Joe and I had Jeremy making eye contact. ABA did in one week what no one here could achieve in three years! Andrea is IDP nurse could see the difference after one week. By the second week, Jeremy was looking at us to get our attention and he was much more aware. Jeremy continues to improve in this area.

About this time, Margie SLP, wanted to try the picture exchange system with Jeremy, since this interfered with the point response of the ABA that I was working on and because I could already see the results of ABA, I put the pictures on hold. Let me say, in the three years we have been involved in the child development program, no one has told me that Jeremy needed to point, to gesture or how to achieve that. This has taken Jeremy a lot longer to get the hang of but he is coming along. It is amazing how much it helps with Jeremy's ability to communicate.

Thus, I have only touched on a few of the simple things that ABA has taught Jeremy in three short months. I can't wait for the professionals to get here and we will be off like a rocket!

At this time, I will go over what my grievences are. First, in September of 1996, we were taken off of 'Theraplay' and told by OSNS that eight sessions were all that there was. I was told that

Jeremy had gone as far as he could with 'Theraplay'. I know now that was a blantant lie. In fact, Evageline (Theraplay Consultant) says "That if a child does well with Theraplay, you could do it 5 days a week. Also you should never stop it cold turkey but instead go from once a week, to every second week, then to monthly." At about this time, Jeremy not only got dumped from 'Theraplay', we got dumped with no therapy whatsoever for two months. In November of that year, Dr. Burrows sent a letter to OSNS stating that Jeremy would require lots of ongoing OT/PT, speech/language therapy, and play therapy. This was obviously ignored because we have never got lots of anything except excuses. If we get OT we don't get speech, if we get speech, we don't get OT, etc, etc. Also in June of last year, we went back to 'Theraplay' as it was the only intervention that had showed any signs of improvement for Jeremy. Almost one year later.... when we should of never stopped.

In July of last year, Margie went to a conference on ABA in Vancouver. When she got back, she asked Steve (Liddiatt) if she should tell me about it. Steve told her "No, don't tell her, those people are fanatics. Theraplay is good enough. I would like to say that it is neither Margie nor Steve's right to make that decision for myself or Joe. This is our child. We should of been told of every option, every choice available to us especially when Jeremy is so severely delayed!

Am I angry? You bet I am! Now everytime I turn around I hear how fantatical the FEAT of BC group are and how their upcoming converance on ABA is only an advertisement for themselves. It is sad that the **egos** that are involved in these government agencies are so big and so fragile that they are put ahead of proven medical research and more importantly, the well-being of children. That is with the exception of Andrea White and Susan White of the IDP, who are open-minded and concerned enough about little children to go to the conference.

Now onto the matter of resources. Until I myself started researching what was available to me in this area, I was never told about supportive child care. I never knew I could get help from them. So not only has my child been denied proper, consistent treatment, I have been treated as though I was an imbecile but I was also denied, by not being told, of any resources that were there to help me.

So I am here to ask for our share. I am aware that there is money available to me through supportive child care and the feel this money is best put towards having a one-on-one work with Jeremy in his own home enviroment hence, in-home daycare. I know there is a 107.00 a month, that I have been waiting for since December and would like that put into place also. Considering that I make that out to be about a total of over 800.00 a month - 200.00 until June 1998 for Julie, there should be about over 600.00 left over to come to Jeremy's care. Out of that money, I will then pay Andrea to continue on with her 'Theraplay' and put the rest towards a one-on-one for Jeremy as a in-home daycare.

I will a wait a speedy reply to this letter as we have certainly waited long enough for funding, treatment, etc. and don't have the luxury of time on our side.

Sincerely,

Barbara Rodrigues

Penticton, B.C.