

WELCOME to



MY HOME

Hi. Welcome to my home. I think. I mean, maybe you're welcome. I'm not sure yet. When I get to know you, I'll know for sure. My child has a disability and I need help to do all the things he needs done. So I need you. He needs you too, because he gets worn out and bored with me and sometimes dislikes me about as much as I sometimes dislike him (Please don't start making judgments about me – we just got started. It's just that I'm honest, and as much as he's the sole reason for my existence, there are times when both of us wear thin).

Your agency sent you here. I called for help, but I don't get a choice of who comes into my home and into my life. You come at your convenience, usually between 9am and 3pm Monday through Friday. I'm on my own evenings and weekends, when my other children tug at me and want me and feel slighted and offended and I feel stretched to my limit. You call and tell me you're coming Tuesday morning so I put the stack of unanswered mail and the unpaid bills in the cabinet with the cereal bowls, race dirty and clean clothes up and down the stairs, shove toys and unmated shoes in closets and under beds, and run the gauntlet with Fantastic to get fingerprints off everything, and then you call and tell me you have to cancel because of a meeting. Oh sure, I understand – Yes, that's fine – Friday afternoon? Well, I was going to try to go to the library and maybe take a nap. What? Oh, that's the only day you have? Well, sure, I know it's important that you come. And we really need your help. Fine – Friday at 1:30. We'll be here.

My husband resents people coming in and out of our home. He says he feels as though he is living in a goldfish bowl. He says getting help means sacrificing our privacy and spontaneity. He can't scratch his stomach as he walks down the hall in his shorts anymore. Now he has to have clothes on and suck in his gut and put on company manners. And he really hates it after you leave because sometimes I cry because I feel inadequate and stupid and foolish and just plain wrong. Sometimes you make me feel this way when you act suspicious of what goes on when you're not here and try to trip me up when we're talking to find out if I'm really doing the goals and objectives – or if I'm just taking the money and fudging the paperwork. Sometimes it's nothing you say or do – it's just that your perfectness unsettles my motherness.

Sometimes when you are great I feel threatened, and because of others who came before you, I feel judged and talked about, as though you have met with others and have developed a plan to implement on me.

I can't always tell when you're real, but my son can. So I watch him. If he responds and welcomes you, then I set aside my needs and cares and let you have everything I have, including my son. I have to trust you because he trusts you and looks forward to your step on the porch.



What? Oh good grief! I forgot your paperwork again! Wait, I know it's here somewhere. I was working on it last week just after the hot water heater burst and right before my husband and came home laid off. Wait—I think I wrote on the back when the bank called about the deposit to cover the overdraft. Yeah—I found them! Right behind the peanut butter—wait—I'll just wipe them off a bit.

You know, I used to be normal. I used to have control over my life, my time, my home. Have a child with a disability turned my life upside down. My priorities changed.

What I would settle for changed. What I would ask for changed. All that changed because my child needs things and people and ideas and funding. So my life consists of meetings, regulations, documentation and paperwork, social workers and agency people, policies and procedure manuals and administrative decisions, delays and rumors of delays in checks, people not showing up when needed, people quitting, and people showing up when they're not needed.

Please don't judge me, and I'll try not to judge you. You see, in the long run, if I don't measure up I am still his mother. So we are stuck with each other and will make the best of it. Help me to grow. Help me to become better. Accept me as a person – not some perfect saint. I really DO know my child better than anyone else, so help me express that and put it to best use. Walk with me a ways, not to judge me, but to understand my role within the heart of my family. Give me tools and words and people that, like pieces in a jigsaw puzzle, interlock to allow for my strengths to compensate for my shortcomings.

Please don't push me past my endurance, because if you do, you'll see me at my worst; short-tempered, impatient, inflexible and emotional. I'm no good to my son then, either. Each one of us has that fine line. I try to recognize when I'm approaching my line, and usually that's when I'm most cranky and complaining to you. Please realize that one facet of me is the tired b _ _ _ _ , just as real and acceptable as the superwoman who overcomes unbelievable obstacles. There are sunny days and then there are thunderstorms – all part of a temperate climate.

Well, anyway – HI. Welcome to my home. I think.

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