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# The Value of Therapeutic Relationships: Conversations after 30 years Rhoda P. Erhardt

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# **History**

At the age of 4 years, with the diagnosis of cerebral palsy, spastic diplegia, Jodie was referred by a physiatrist to the Easter Seal Mobile Therapy Unit In Fargo, ND.A bi-weekly occupational therapy home program was recommended to develop hand coordination and functional hand use. When Jodie was enrolled in preschool, prescribed therapeutic activities were integrated into the daily schedule by teachers and volunteers, trained and supervised by the

author, an OT practitioner (Erhardt, 1971). Occupational performance goals were to improve participation in the domains of education, play, and self-help activities, such as dressing and feeding (Erhardt & Merrill, 1998). To facilitate achievement of those goals, one of the primary objectives was to improve postural control, the foundation of gross and fine motor skill development(Figure 1) (Erhardt, April 13, 2009).



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During that time, Jodie was one of 10 children that participated in the research for this author's master's

thesis that addressed that topic of postural control (Figure 2) (Erhardt, 1974).



In elementary school, she received services from Easter Seal staff and OT students during their pediatric field work. PL 94-142, Education for All Handicapped Children Act, was passed in 1975 "to assure that all children with disabilities have available to them . . . a free appropriate public education which emphasizes special education and related services designed to meet their unique needs"(U.S. Department of Education, 2019). Occupational therapy services were transferred to school systems and the Easter Seal program was closed. The author's subsequent private practice included consultation contracts with the schools, providing intermittent consultation and communication with Jodie and her family until she graduated from high school, and the author moved out of state.

## **Retrospective Views from Client and Therapist**

Almost thirty years later, when she was 46, Jodie reached out to reconnect, and our fascinating 7-year email correspondence began. These selected excerpts from our documented 80-page dialogue demonstrate the distinct value of early childhood and school-based occupational therapy, as perceived by Jodie and her family.

Jodie: I've been wanting to write to you for a while

and changed the lives of me, my family, and so many others. I've come to the conclusion there are not words enough in any language to convey the gratitude in my heart that has carried me through the past 40 years. Working with you and other OTs opened up the world to me and made the impossible possible, made a disability an ability. During the many years since we last spoke, I've done many things and maintained my abilities without a day of therapy, which I have discovered recently is a major feat.

This year, however (at age 46), I've been having mobility issues that I have never had before. MRI results came back 95% certain that I have multiple sclerosis on top of my cerebral palsy. Thought maybe you might know something more about CP & MS. Any knowledge you have I would greatly appreciated. I look forward to hearing from you. Welcome to my new Journey.

**Therapist:** Hi Jodie. It is great to get this message from you, reminding me of everything we did so very long ago. You were one of the first kids referred to me when I started my private practice, and I learned so much from just knowing you, and problem-solving together. I always thought you could do whatever you wanted, and after a while, the shy little girl did figure out what she wanted, and made sure we all knew it! I we that wan have had to as these all this mare

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specialized in pediatrics, but I will look for anything that will be helpful to you.

The alliance, or collaborative bond, between client/family and therapist has been found to be related to outcomes of treatment adherence and satisfaction in patients receiving physical rehabilitation, including those with musculoskeletal conditions. (Hall, et al, 2010). The main components that contribute to the alliance construct are 1} agreement on goals of treatment and interventions, and 2) the affective bond between patient and therapist (Scaffa, Van Slyke, & Brownson, 2008).

Jodie: I'm not quite sure what to say, how to say it, how to feel. I've always known thatbonds form andyearsgo by, but all it takes is 5-10 minuteson the phone and we're filling in blanks as if time never passed. I'm all over the place emotionally right now, but the results are in: 100% I have RRMS (relapseremission MS), which means I'm going to live a very long time. They found me a therapist that specializes in MS & CP together. The thing I keep hearing is CP & MS are different. CP doesn't change. I get that. I also know that CP does change if I don't move. I'll lose ability, and then a whole host of other things can happen, contractures, scoliosis, pressure sores, etc.

Therapist: Let me explain what I think they mean when they say CP doesn't change. The insult to the brain (lesions/damage) is a one-time thing, before, during, or shortly after birth. The damage doesn't continue, whereas MS is a disease that does continue, usually erratically, and not predictable. Just what you need, an unpredictable life. As you know, CP will cause your body to change unless you keep mobile. You are reacting to a new diagnosis and your emotions now are so appropriate. You will take time to grieve the possible loss of still more health. I always look at the positives in our lives, not what happens to us, but how we react. To me, you are the queen of strength and adaptability. You have educated yourself about everything important. You will continue to do that. The people in your support system can give you different types of help. I see my role as giving you explanations, telling you often how smart you are, and sending my positive energy your way.

> Persons with disabilities are at significant risk for additional or secondary disabilities,

that a comprehensive health promotion component is included in rehabilitation programs, and that types of secondary disability are discussed in terms of its preventability (Marge, 1988).

Jodie: Glad we got a chance to talk yesterday, my mom had lots to say about you over the weekend when I asked her how she felt about me reconnecting with you. She reminded me of times I was "mini Rhoda", teaching kids younger then me how to do things they supposedly couldn't do, or telling a kid not to "frog sit", or Rhoda might catchhim doing it.

In the family-centered care model, the longterm care of children with cerebral palsy considers parents as key resources for their children's lives, and supports collaboration of families and practitioners within a child's intervention program, which is based on the values, preferences, priorities, and needs of families, in order to improve the child and the family's quality of life (Trabacca, 2016). One of the most rewarding aspects of being an occupational therapist working with families in homes are the close relationships built and maintained through many years. There is no question that a team of family and professionals can make a real difference in a child's life, and those experiences can change the course of the professionals' lives as well (Erhardt, June, 2017).

Jodie So, I am sitting in the clinic with my sister, waiting for the Dr. who walks in, starts talking, showing scans, explaining the lesions, different meds, etc. By this time I'm just looking at the wall, then I stop her and say, "I have CP and MS. CP is my normal. Tell me what kind of MS and how to fix it, because that's what I need to know right now. The Dr. was floored and said, "Sounds like you guys have learned a lot and have a support system built already. Most people we see don't". I said, "Did you ever see CP and MS together before?" "No," she says. I said, "You have now! Nice to meet you. Welcome to my team".

**Therapist**: I have kept in touch with some of my CP patients as they grew into adulthood, and they have told me about problems that you have identified and

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flexibility. As I said, I don't know much about MS, except a very good friend, older than you, has had it for at least 30 years, and although she is in a wheelchair now, she is still working as a speech therapist! I will continue to look for information.

**Jodie:** Don't worry about not having answers to things I ask!! Don't be afraid to ask me anything either. You have the knowledge. I have life experience. Together that is golden. As for MS we will learn together!! I'm strong, a fighter, I know what I want to do and maybe how to get there but right now I'm so broken. You held me once, carried me, stood beside me walked with me, and we learned together. We're about to do it again.

> In the medical profession, trust is seen as a global attribute of treatment relationships, encompassing satisfaction, communication, competency, and privacy. A patient's trust in his or her therapist is positively correlated with self-reported measures of health status and overall quality of life (Scaffa, Van Slyke, & Brownson, 2008).

**Jodie**: I may be queen of adaptability but strength not so much these days. At least not inside. I struggle with many things, most of which are completely normal or so I'm told. You know that I often overcome obstacles and exceedothers' expectations. I haven't changed. There's no doubt that I will overcome this in some way as I have done my whole life.

Therapist: Norman Vincent Peale said that "The secret of life is not what happens to you, but what you do with what happens to you." (Peale, 2019). What a powerful quote. We often have curveballs and adversities, a fact of life. Really, in life there is very little that is completely within our control or influence. How we deal with life's situations is what becomes really important. The first step in changing how we deal with life's situations is to change how we see the situation. This of course is easier said than done. We must try to view the situation as neutral or positive. Ask ourselves "what can I learn here?" or "how can I grow?" The next step is to act upon our new viewpoint. Stepping into action is an important step in locking in the new viewpoint. Rather than fall victim to the circumstances, take action. Finally, seek to review what we have learned. It's possible that life

continues to send us similar challenges, crises or problems as teaching moments. As we learn these lessons and incorporate our learning, the pain lessens. Wow! Lessons and Lessens!

> Client-centred rehabilitation includes more decision-making goal-setting and between individual clients and professionals. It refers to a philosophy or approach to the delivery of services that reflects the needs of individuals and groups of clients, and awareness ofthe emotional challenges of living with a long-term chronic illness or disability (Cott, 2004).

What I admire in people is the effort they put into doing what has to be done. It's all about how you live your life, not whether or not you reach all your goals. I never mind mistakes in others (or myself), as long as the effort is made to learn from them. I'm lucky that I still have the desire to learn, to function, and to enjoy my life, even though there are many things I can't do anymore because of the physical limitations of my own aging.

### **Update: Age 53**

**Jodie:** New MRI results in my chart: Similar to or unchanged since the last one four years ago. Other findings: No active or continuing lesions relating to MS, just some gray areas of degeneration consistent with someone who has a history of cerebral palsy.

#### Final Thoughts

An unexpected result of the reconnecting relationship between therapist/client was the realization that postural control is now a shared issue, since many of the task modifications and adaptations taught to Jodie so many years ago are now the same or very similar strategies and equipment used by this 87-year-old author to maintain as much independence as possible during the relentless aging process. In fact, at age 60, the dream of designing and building an accessible home was accomplished, and it has contributed to the ability to maintain functional ADLs for the last 27 years (March 31, 2008). Examples include grab bars in bath rooms, walk-in shower, battery-operated bath recliner chair, a very stable walker (Figure 3.), and 3 hand reachers, placed strategically in office, bedroom, and living room.

Still, the inevitable falls do occur, an opportunity to share experiences.



Jodie: I fell a few weeks ago. I'm fine, but can't explain why I fell, which scares me. Unexplained falls are a sign of MS relapse. I was wearing socks on a bathroom floor, using my wheelchair as a walker, when it happened. Most falls I can explain, like a crutch slipping on water. Took me 20 mins to crawl into my room. I gathered pillows, was able to get up unharmed, but shaken. Gone are the days when I can instead to be the crawling is even more difficult on a

on an arthritic knee. Thank god I don't fall often but it scared me for sure. I didn't walk for a few days, but am walking fine now. This winter weather isn't helping much. I ache everywhere for no reason or am stiff in places I didn't know I had, but so are many other people.

Therapist: OMG! That is the story of my life. I used to fall on the ice every year in the winter but never

kept falling, but started breaking bones when I fell. The worst was the first. I was getting into the filled bathtub, reached for the grab bar that I had installed when the house was built eight years earlier, and stepped in with one leg. As I slipped, still holding on the rail, I heard a big crack, and thought, wow I can't believe the grab bar came off the wall, which had solid plywood behind it. When I looked at my arm, I saw that it was not holding the grab bar, in fact it was turned backwards and was just hanging there. For some reason it didn't hurt, but it was useless, so I pushed myself up and over the tub with my other arm and my chin, managed to stand up somehow, grab a big towel, and walk into my office to call a neighbor. She came over, helped me get into a robe, called 911, and off I went in the ambulance. I had a huge break in my humerus, right arm, and it took two years to heal. That is another story, Jodie.

## Acknowledgments

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