Original Research **ISSN 2835-6276**

American Journal of Medical and Clinical Research & Reviews

Climbing out of the Box: Challenging Cases, Issues, and Ideas in the Field of Developmental Disabilities (Part I)

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Received: 07 Feb 2025; **Accepted:** 15 Feb 2025; **Published:** 25 Feb 2025

Citation: Dean D. Alexander. Climbing out of the Box: Challenging Cases, Issues, and Ideas in the Field of Developmental Disabilities (Part I). AJMCRR. 2025; 4(3): 1-10.

Introduction: the Challenge - D.A.

With some of the toughest challenges in developmental disabilities, clients and clinicians find themselves in a box. These challenges may be patterns of severe maladaptive behavior, but also problems of learning related to self-help skills, social and cognitive development. The client may be in a box because he or she has difficulty letting go of his/her way of doing things in the world. Perhaps he only feels safe playing by his rules. Perhaps she gets much warranted attention. Perhaps there are medical or genetic factors that complicate. But for parents and teachers, care-takers and clinicians, their special person is "stuck."

Trying to help a child or adult to climb out of a box is no small task. After repeated attempts we may feel stuck within our own limitations. The helpers begin to feel helpless. At that time it is worthwhile to try to think outside of the box. What did I miss? Where can I go? Tear up the text and let's start over! This series of vignettes is about the journey of getting "unstuck" - of approaching challenging problems in non-traditional, outside-of-the-box ways that in turn allow our clients to experience greater independence and dignity.

In 1980, Marc Gold, Ph.D. published a popular book titled Try Another Way (Research Press). That would have been a good title here. We do agree with Dr. Gold that the training situation should be tailored to the learners needs, should be fluid and dynamic, and that "the most effective demonstration of a learner's ability and personality will naturally occur when he is actively engaged in learning' (p.4, Try Another Way). Yet Dr. Gold's book focused primarily on new views of task analysis, a systematic approach to teaching widely used in Special Education over the past 40 years and beyond. In contrast our case vignettes are not system-specific, systematic, or philosophical. Instead we propose to take our readers on real case adventures where client and clinician break free of constraints through methods orthodox and unorthodox. Some of the cases and clinical approaches the reader will encounter include: teaching independent feeding using a ladder or tricycle; potty training for infants; shoe tying with "wired" laces.

Some of the approaches described here will reflect pages in our history rather than pages from a modern practitioner's manual. The first case we present - A Step Up - relied on a single step, single trial

avoidance conditioning approach to develop a sustained voluntary palmer grasp for independent feeding. When I taught Barbi (name fictitious) to feed herself on the first rounded rung of an immovable ladder, it reflected Edward Seguin's work more than a century earlier. We had approvals from her parents, from our center's Human Rights Committee, and later presented Barbi's accomplishment at the Western Psychological Association in Coronado, CA. Dr. Ball and I recognize that avoidance approaches are likely to be viewed differently today than in1970. That said, the challenge remains for new generations of therapists to pick up the gauntlet of creative and currently approved approaches to formidable problems of human behaviour.

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Introduction To Self-Help Skills

In what follows I hope to provide you with a brief glimpse of an exciting era of hope and change, one in which the learning potentials of severely and profoundly retarded people were about to be seen in an entirely new light.

When we accept the degradation of another human being we surrender a part of our own humanity. This acceptance may arise, not from willful neglect, but from despair of the possibility for change - an assumption of inherent and insurmountable limitations of the subject of our concern. Such assumptions can have dehumanizing effects in the day-to-day treatment of individuals with profound intellectual disability. That fact was graphically illustrated during my visit to Louisiana's Pinecrest State School, 1964. My host, Cecil Colwell, showed me a large room with a circular floor tapering down to a drain at its center. In the past, adults with profound disability were herded into this room and, like cattle, were hosed down with their accumulated filth being washed down the drain. Then, as someone familiar with institutional routines, I was astounded by what came next on the tour, direct evidence that these individuals had a capacity for learning beyond what was previously imagined. That included a documentary film featuring a boy with profound disability feeding himself in a family-like setting. A dramatic reassessment of the learning potential of such individuals was beginning to lift that curtain of despair.

This paradigm shift arose from the practical application of a learning theory, B.F. Skinner's operant conditioning. In collaboration with Marian Breland, herself the mother of a child with intellectual disability, Colwell incorporated the principles of operant conditioning in the training of self-help skills. A new day of hope and unanticipated possibilities was about to dawn. - T.B.

A STEP UP

"Dr. Ball, Dr. Ball!" I gasped running up the steep flight of stairs, "Barbie held on by herself when I put her on the swing!" Dr. Ball was not yet "Tom" to me, though later we would become colleagues and the closest of friends. It was 1970. I had just graduated from Brown University and driven cross-country to work with Dr. Ball in an intensive behavioral intervention project he had started.

Barbi was an 11-year-old girl with profound intellectual disability, deafness and blindness due to Congenital Rubella, a condition resulting from German measles contracted during mother's pregnancy. Barbi lacked all self-help skills, including independent feeding, because she was unwilling to grasp and hold on to any object such as a spoon. We had tried physical guidance approaches where we placed our hands over hers. While she did not resist we were unable to "fade" our support without the spoon falling.

One afternoon during a play break I put Barbi on an outdoor swing. I placed her hands on the suspension chains with my hands over hers for support. I could feel her holding on and reduced my support! Serendipity! Sometime later I approached Dr. Ball again with almost equal excitement. In my hand was a long handled ice-tea spoon requisitioned from Denny's. (Belated thanks!) In a utility room off of one of the main corridors was a sturdy yellow ladder with round rungs, built into the floor and ceiling. The ice-tea spoon could be bent into kind of a z shape and then duct-taped to one of the middle rungs. We would teach Barbi to feed herself on the ladder! She could hold on to the junc-

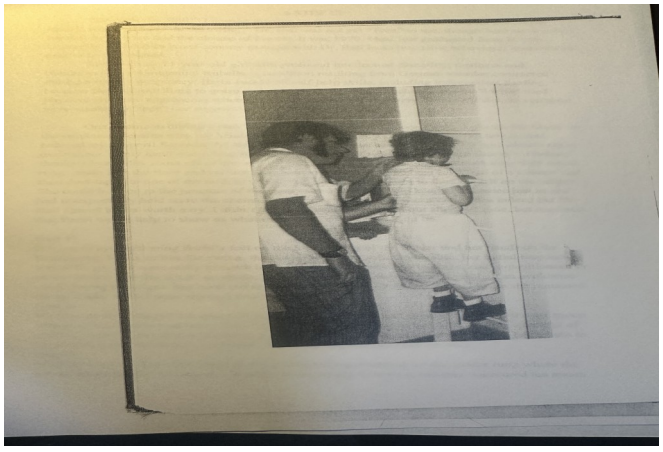
ture of the spoon handle and rung to keep her balance just as she had unexpectedly held on to the chains supporting the swing. It was a crazy idea indeed but Dr. Ball agreed it was worth a try. I didn't have all the steps planned out ahead of time, but reasoned that Barbi would help to show us what the logical next step should be.

Step 1

We began by positioning Barbi's feet on the lowest rung of the ladder and her hands on the fourth rung. Since, unlike the swing, the ladder was very solid and stable, her initial response was to let go. We were ready to catch her as she momentarily lost balance, and re-positioned her on the ladder. She did not let go again, having learned to grasp and hold through an avoidance conditioning paradigm. She received spoonfuls of pudding- a favorite treat- while she remained on the ladder so that soon she anticipated the training.

Step 2

We affixed the z shaped tea spoon to the fourth ladder rung and filled the bowl of the tea spoon with pudding. I prompted her to feed from the bowl of the spoon by using another spoonful of pudding to entice her in that direction. Fairly soon she would independently move her mouth to the ice-tea spoon secured to the ladder. No prompting needed. (See photo.)



Step 3

What to do next? Barbi had developed a good grasping response on the ladder rung where the ice-tea spoon handle was taped. I hoped that she would hold on to another unsecured tea spoon with a short built-up handle, which we then placed at the same spot. Bless her heart - she did hold onto both, while still feeding herself from the bowl of the z-shaped ice-tea spoon.

Step 4

We were confident that Barbi was confident standing on the ladder. As she held onto the rung with her left hand, we placed the pudding-laden, unsecured spoon in her right hand and prompted it toward her mouth. She fed herself. When we took back the unsecured spoon, Barbi returned her grasp to the ladder. We repeated the sequence until Barbi had finished the pudding.

Step 5

We positioned Barbi to stand next to the ladder and take the unsecured spoon from us to feed herself. We allowed her to hold a lower ladder rung with her left hand in order to make transition steps small and feel safe.

Conclusion

Barbi's parents moved to the East coast and wanted her to be close to them. We received a lovely thank you note several months later for the work we had done with their daughter. Barbi was doing well and feeding herself. We obtained their permission to do a slide presentation of our step-by-step training procedure at the1971 Western Psychological Association meeting in Coronado (San Diego) CA.

LOOKING BACK

At the time I proposed this approach I had never heard of Edward Seguin (1812 -- 1880). Dr. Ball's book on sensory education, which contains a chapter on Seguin's ladder training and other imaginative approaches, had not yet been published. More than a half century later ITARD, SEGUIN, AND KEPHART : SENSORY EDUCATION - A LEARNING INTERPRETATION (1971) remains a dynamic dialogue between past and present. It challenges clinicians to view their field in new perspective, and look outside the box for unique, hard-headed solutions to unique problems. Feeling Barbi holding on to the chains of the swing under my own hands was a bit of serendipity. Serendipity be praised! Looking back I feel that I was grasping the hands of a child with a chance for new independence, as well as the hands of two kindred spirits...Dr. Seguin and Dr. Ball.

A Trike Is a Trike Is a Spoon (?)

Like Barbie, Kathy had not learned to feed herself independently. But her problem was different. Kathy would hold on to the spoon in front of her body and simply not move it. Her hand was as fixed as if she were a statue.

Blind and deaf, Kathy was a 12-year-old girl with Down's Syndrome. She lacked almost all of her basic self-help skills, but since self-feeding leads to its own reward- food, this would be a good place to start. Kathy had adequate fine-motor skills and a very good appetite. She responded readily to our physical prompts, a touch on the back of her hand, to initiate movement of the spoon toward her bowl or plate, and then would bring the spoon independently to her mouth. All we had to do was to "fade" our prompt by making our touch to the back of her hand lighter and lighter. This would be easy- or so we thought.

Over more than a week period we meticulously tried to fade our one-touch prompt, which initiated Kathy's feeding cycle. But after each spoonful she would return to that fixed position, waiting for the next prompt to feed herself the next spoonful. Moving the prompt toward her elbow was no more successful.

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Clearly Kathy had developed a strong dependence on the attention aspect of training. But how do we provide less attention than a single feather-light touch with one finger? Maybe we could rely instead on Kathy's good appetite and enjoyment of different foods. Okay. We put the spoon in her hand, her plate close to her body, and withheld our prompt. Kathy held the spoon in her customary position. No food eaten. Next meal same result. Some Ensure provided for nourishment under a nurse's supervision after a third training failure that day. Next day: similar results- or more to the point, lack of results. Being hungry didn't break the prompt-dependent feeding cycle.

Did I say cycle? In our equipment store was a child's tricycle. Our clients were too big to ride on it but it gave me an idea. I detached the black pedal from the spike that supported it, and taped a spoon to the spike. We turned the trike upside down and

positioned it so that the front wheel was aligned with Kathy's torso. When the wheel was rotated the spoon would be level with Kathy's mouth. At the bottom of the rotation the spoon would come in contact with her bowl of food (mashed potatoes mixed with other foods to start), which was tilted to make "scooping" easy. I put Kathy's hand over the spoon and held my breath. The mere weight of her hand on the wheel was enough to make it turn and scoop through the mashed potatoes. With little effort, she brought the spoon up to her mouth in the circular motion dictated by the wheel. The potatoes were eaten with satisfaction before Kathy dispatched the spoon on its next cycle. Kathy learned to feed herself fairly quickly thereafter. She always maintained a circular motion at the dining table.

LOOKING BACK

Kathy, like many other clients with intellectual disabilities, are more resolute than staff. They become very invested in whatever payoff they have learned to anticipate- in this instance, staff prompts during mealtime. We were able to provide a new payoff-independent feeding- only by thinking outside of the box. - D.A.

Paganini with a Spoon

Thomas S. Ball

We enter a ward in a facility for profoundly developmentally disabled children. We observe some school age children dressed in diapers, lying on their backs in cribs. A human catastrophe unfolds before our eyes. We avoid the awareness that in a cruel stroke of fate a normal child of our own could have come into existence this severely mentally impaired.

The typical feeding method on the ward entailed no active participation by the child in the feeding process. He was fed while lying on his back. Pureed foods were introduced by a spoon which was quickly withdrawn with a scraping motion against the upper teeth. Immediately afterward any excess food was scraped off the chin. Milk from a baby bottle was squirted into his mouth without his engaging the nipple. Helen's technique, in contrast, emphasized the boy's active participation in the feeding process. Both of the boys I studied were fed in the upright rather than in the recumbent position. With the first boy, an 11-year-old with a probably overestimated IQ of ten, she playfully thrust the nipple in and out between his teeth and a teasing "tug-of-war" ensued in which the bottle was moved back and forth or up and down while he tenaciously clung to the nipple with closed teeth. In spoon feeding, the utensil was held in the mouth during which he repeatedly bit down on it until the food was removed. Whenever biting slowed down or ceased, it was reinstated by tapping the spoon against the upper and lower front teeth. To provide widespread stimulation, the nipple was occasionally moved from one corner of the mouth to the other. With the second boy, a 6-year-old, the stream of milk from a spout cup was widely distributed inside his mouth including various parts of the tongue and cheeks. The milk passed back to the throat on both sides of the mouth thereby stimulating several locations. This provided a richer sensory experience for the youngster than the mechanistic sucking associated with routine care.

Scientific evaluation of Helen's technique involved its temporary withdrawal followed by its reinstatement. The first child soon reverted to regurgitation after being placed on a feeding routine that was then standard on the ward, but that quickly ended upon the restoration of the special feeding technique. However, in response to the withdrawal

phase of the experiment and despite the fact that he was physically well, the second boy lapsed into a state of listlessness and apathy and seldom smiled. He reverted to passivity during the feeding process. The alert, smiling expression and postural anticipation of being fed gradually diminished. He lost the obvious zest and joyfulness which he had previously shown toward eating. There was an increase in chewing and sucking on items such as his bib. Masturbatory behavior also seemed to increase. We soon became alarmed over his response to the standard method. It was as if he was abandoning his grip on life that he was slipping away before our very eyes. We quickly reinstated Helen's method and, much to our relief, he demonstrated an overall recovery including the cessation of regurgitation.

LOOKING BACK

From the very first I sensed that Helen's devotion to her work was exceptional, inspirational and spiritual. It was a search for and discovery of humanity in the midst of desolation. She anticipated the death of a child before anyone else and when it occurred she would drive to the sea shore to bid the child a final farewell. It was an honor to have known you, Helen. You were Paginini with a spoon. - T.B.

Babies Are Smarter Than You Think

Sometimes, in the quest for knowledge, it is the teacher rather than the student who is the greater beneficiary. Such was the case when I, as a consultant, was privileged to meet Lela Humphries, a very modest and unassuming lady, who was soon to share her exciting story of infant learning. For several years I had been personally involved in the research and applied aspects of operant conditioning approaches to self-help training for persons with intellectual disability. I had seen even the most disabled acquire capabilities that were, until shortly before that time, commonly assumed to exceed the upper limits of their ability to learn. Yet I was hardly prepared for what I was about to learn. That was in 1971 and, regrettably, the widespread acceptance of the reality of her achievement, has yet to be realized. Here, in her own words, you get a brief glimpse of how she achieved a significant amount of control over bowel eliminations as early as five months of age. This method was employed successfully with her two normal sons and one with Down's Syndrome.

In 1947 our first son was born, a normal healthy boy. He was a bottle fed baby, but I held him for all his feedings and noticed each time he had a bowel movement it was during feeding.

I had been given a small plastic potty at a shower, so decided to use it, the primary reason being to save soiled diapers. It was a simple enough thing to do, as I could always tell by the facial expression when the movements were going to occur.

At six weeks of age I started taking the potty and toilet tissue and set [them] beside me each time I sat down to give him his bottle. I would unpin the left side of his diaper, place the child's head in my left arm (I'm right handed) and hold the bottle in my right hand. The moment he made his facial expression, indicating he was about to have his BM, I would not take the diaper off, just reach underneath and pull diaper off buttocks, place plastic pot between my legs and place his buttocks on it' leave the diaper over front for self-preservation, especially if a boy, lean baby back on arm and continue feeding him his bottle. His position was the same as if he did not have the pot under him. He did not make any kind of fuss.

At five months we made a trip back East. I left him with my sister-in-law while I went shopping. On returning, she related to me the baby got very fussy and nothing seemed to satisfy him. She finally decided he might want on the potty, but instead of placing him on his regular pot, she held him upright and rested him over the edge of regular toilet. He had his BM and was happy after that. I felt his bowel training was reasonably completed at six months. The bladder training was longer.

I was excited by her account, not only by the immensely practical and interpersonal implications of her method, but also from a theoretical standpoint--it was the purest example of operant conditioning that I had ever encountered. Furthermore, it was completely foreign to our everyday practices in teaching children. In this context, the baby led and the parent followed in response to the infant's spontaneous behavior (facial expression signaling an impending bowel movement). He was never urged to withhold a bowel movement. Rather, in response to his behavioral cue, she introduced the plastic pot which became part of a chain of events leading to elimination. The ultimate reward at the end of the chain was the relief occasioned by the passing of the stool. That relief reinforced the entire chain including contact of the potty with the buttocks. In this way an additional step was added to the otherwise automatic process of elimination. For the baby, it was effortless learning based upon an internal cue rather than a mechanical placement on the potty.

Looking Back

Lela's independent discovery of an operant conditioning training method was the result of her willingness to innovate combined with an acute sensitivity to each child's behavior. It was an exquisite expression of empathic mother-child communication. My analysis of her achievement inspired a carefully controlled study with four babies in Italy. It conclusively confirmed the fact that successful toilet learning could be achieved at so early an age. Years later I learned that mothers in such distant places and diverse cultures as are to be found in India, China and among an East African native population, highly perceptive mothers had discovered basically the same operant conditioning training method. It is ironic that in so highly sophisticated culture as is found in the United States, the age for the onset of toilet training has become progressively delayed. Could it have anything to do with a 24 billion dollar "diaper industrial complex" with its virtually limitless capacity for advertising that in our supermarkets diapers are being sold for "babies" up to 50 pounds? - T.B.

No Sale!

One of my earliest experiences in the application of operant conditioning training methods with severely developmentally disabled residents in a state facility occurred during my initial attempts to train a boy of around 12 to remove a t-shirt. That was the first step in the process of teaching dressing and undressing. I put the t-shirt on him and then half removed it so that his face was covered, but he could easily remove it. He was engaging in an act that could be positively reinforced as soon as he himself terminated the frustrating situation by removing the shirt. He did indeed remove the t-shirt but before I could reinforce (reward) him for his stellar performance he did the unexpected-he hurried to the opposite end of the room and in an area with shelving deposited it in the highest cubby hole that he could reach. He just refused to adhere to my plan and, at least for that moment, showed me who

was actually in charge. I ended up eating a generous portion of humble pie. - T.B.

I Just Tied My Shoe!

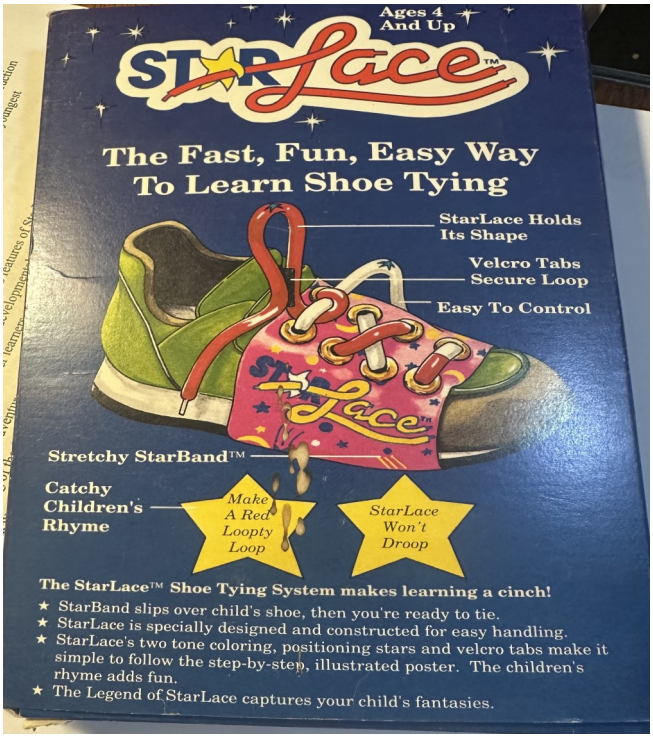
I watched as a man in his twenties with schizophrenia and mild mental retardation tried to control tremors in his hands in order to tie his shoes. He told me that not tying his shoes made him feel like a child. Unfortunately, by the time I had come up with a possible solution to his problem, I had taken a position several hundred miles away.

The basic nature of a shoe lace is to be a floppy and less than cooperative thing. But if the same shoe lace were to have an element that gave it more stability maybe it would have helped my former client master this fine-motor task. And maybe typically developing children could learn to tie at a younger age than four to six.

I purchased several gages of copper wire, and snipped off the plastic tips from a half dozen shoe laces. Then I inserted the wires, taped the ends, and created my first prototypes of "wired shoe laces". Obtaining permissions from the parents and administrators of the day care at Lanterman Developmental Center, I proceeded to teach first the four year old, and then the three year old children to tie shoes independently during my lunch hour. The children and their parents were delighted. I was excited (and often hungry).

I then took my wired shoe lace to high functioning clients on my assigned residence at Lanterman. They too benefitted from this more cooperative lace that flexibly bent but stayed in position in mid-air even as instructor and student moved their hands. It was easy to demonstrate all of the seven sequential positions required in order to tie a bow.

But my experience with normal children and adults with intellectual disabilities suggested additional features that could make learning even easier. If the lace were half red and half white, the two halves of the lace would be easier to differentiate as they were moved through space. A marking such as a star could be placed on the portion of the lace to be pushed through to form a second loop. If the formed bow could be "cinched" with a small piece of velcro the cinch would provide added control. Finally if shoe tying was guided by a teaching rhyme of step-by-step instruction a floppy lace could become a "StarLace":



"Red Over White
And Hold On Tight
Aim The Red Lace
Through The Hole Into Space
Pull Them Both Through
Dean's Tying His Shoe!

Make A Red Loopty Loop,
StarLace Won't Droop.
Over We Roll
The Star Stops At The Hole.

Now Push Through The Star
But Don't Push Too Far
Pull The Star Through
I Just Tied My Shoe!

Star Lace was manufactured with the patience and technological expertise of wonderful people in Fall River, Massachusetts and Pawtucket, Rhode Island. It was carried in Nordstrom department stores along the west coast. My wife Margrette, Anne La Verne and I did shoe tying instruction clinics at various Nordstrom outlets on Saturday mornings and afternoons. Our youngest learner(able to tie a bow independently) was two year ten months old.

LOOKING BACK

Learners benefitted differently form the various features of Star Lace. In general, our youngest learners and those with intellectual or developmental disabilities appeared to rely most on the stabilizing elements, while older learners consistently utilized the teaching rhyme.

Star Lace was an adventure complete with twists and turns (sorry about the pun). At the beginning of 1990 the product was written up in the Los Angeles Times (Lynn Simross) as "new and innovative", and at the end of the year as one of the ten best little products of the year. - D.A.

Testimonial from Laura Schreibman

I have read the materials you sent and greatly enjoyed them. I absolutely love the stories of imaginative approaches to changing behaviors in individuals with developmental disabilities. The stories are well-written and definitely engaging. I found myself rooting for you (and Tom) and for the individual involved. I am certain people either entering the field of special education, or already in the field, would find these stories interesting and encouraging.