

REAL WORK IN THE REAL WORLD IS GREAT. HOWEVER...

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IN JUNE OF 2008 I MADE A PRESENTATION AT THE ANNUAL ARIZONA TASH CONFERENCE AT NORTHERN ARIZONA UNIVERSITY. THE FOCUS WAS ON HOW TO ARRANGE FOR INDIVIDUALS WITH SIGNIFICANT DISABILITIES TO FUNCTION PRODUCTIVELY IN INTEGRATED WORK SETTING OVER EXTENDED PERIODS OF TIME . I STARTED BY COMMUNICATING THAT FOR THE FIRST TIME IN THE HISTORY OF OUR PLANET LARGE NUMBERS OF INDIVIDUALS WITH SIGNIFICANT INTELLECTUAL AND RELATED DISABILITIES ARE OUTLIVING THEIR BIOLOGICAL PARENTS. IN ADDITION, THEY ARE AGING MUCH SOONER THAN CHRONOLOGICAL AGE PEERS WITHOUT DISABILITIES. THESE PHENOMENA ARE CREATING MAJOR PROBLEMS FOR PARENTS, SIBLINGS, HEALTH AND HUMAN SERVICE WORKERS, INSURANCE COMPANIES, TAXPAYERS AND MANY OTHERS.

IN THE OPEN FORUM PORTION OF THE PRESENTATION , A NATIVE AMERICAN WOMAN ABOUT MY AGE DESCRIBED A DILEMMA ON HER NEARBY NAVAJO RESERVATION AS FOLLOWS. A COUPLE HAD FOUR CHILDREN WITH DISABILITIES. TWO WERE FUNCTIONING AS SHEPHERDS. THE OTHERS STAYED AT HOME. RECENTLY, THE FATHER DIED AND THE MOTHER HAS BECOME QUITE CONCERNED ABOUT WHAT WILL HAPPEN TO HER TWO NONWORKING CHILDREN AT HER DEATH. SHE ASKED FOR MY THOUGHTS .

WHAT COULD I SAY THAT MIGHT BE RELEVANT AND HELPFUL? WHAT WOULD YOU SAY? I PAUSED, HOPING THAT A MEANINGFUL THOUGHT WOULD MAGICALLY APPEAR. IN ACTUAL TIME THE PAUSE WAS A FEW SECONDS, BUT IT FELT LIKE AN HOUR. I COULD HAVE SAID THAT WE CAN GET INDIVIDUALS TO THE WORK OR WE CAN GET THE WORK TO INDIVIDUALS. SPECIFICALLY, WE COULD MOVE THE TWO INDIVIDUALS OFF THE RESERVATION CLOSE TO THE ENTERPRISES OF PHOENIX OR FLAGSTAFF OR WE COULD ESTABLISH ENTERPRISE ZONES ON THE RESERVATION AND TEACH THEM TO WORK THEREIN. I DOUBTED IF SHE AND HER FRIENDS AND COLLEAGUES WOULD HAVE FOUND THAT HELPFUL.

I ACKNOWLEDGED THAT THE VOCATIONAL SYSTEM I DESCRIBED CAME FROM EXPERIENCES IN MADISON, WISCONSIN; CHICAGO, ILLINOIS; AND, MELBOURNE, FLORIDA. THE KEY INGREDIENTS OF THAT SYSTEM WERE INDIVIDUALS WITH SIGNIFICANT DISABILITIES AND REASONABLE ACCESS TO ENTERPRISE IN THE FORMS OF BANKS, INSURANCE COMPANIES, HOSPITALS, UNIVERSITIES , HOTELS, LAW OFFICES, RESTAURANTS AND OTHER INTEGRATED WORK SETTINGS. I SAID THAT MY

ASSUMPTION WAS THAT THE TWO INDIVIDUALS OF CONCERN DID NOT HAVE REASONABLE ACCESS TO THE ENTERPRISES DEPICTED IN MY PRESENTATION. SHE NODDED IN THE AFFIRMATIVE.

PLEASE ALLOW ME TO DIGRESS. FOR MANY YEARS I FUNCTIONED FROM THE PREMISE THAT THERE WERE ONLY TWO PREREQUISITES FOR INTEGRATED WORK: YOU MUST BREATHE AND YOU MUST HAVE ONE VOLITIONAL MOTOR MOVEMENT. IF YOU COULD NOT BREATHE, WE WOULD REFER YOU TO ANOTHER PROGRAM. IF YOU COULD BREATHE BUT COULD NOT MOVE ONE PART OF YOUR BODY VOLUNTARILY, WE WOULD REFER YOU TO THE REPUBLICANS IN THE FLORIDA LEGISLATURE. A THIRD PREREQUISITE NEVER OCCURRED TO ME UNTIL THIS SOLEMN AND PENETRATING WOMAN PRESENTED HER PROBLEM. YOU ALSO NEED REASONABLE ACCESS TO ENTERPRISE.

I STARTED INTERACTING WITH INDIVIDUALS WITH SIGNIFICANT INTELLECTUAL AND BEHAVIORAL DISABILITIES PRIMARILY IN INSTITUTIONAL SETTINGS IN NORTH CAROLINA (1964 - 66) AND THEN IN FLORIDA (1966 - 69). IN JULY OF 1969 I MOVED TO WISCONSIN AND IMMEDIATELY STARTED WORKING WITH INDIVIDUALS WITH SIGNIFICANT DISABILITIES WHO ATTENDED LOCAL SCHOOLS. SHORTLY THEREAFTER, I ALSO STARTED WORKING AT A LOCAL STATE OPERATED RESIDENTIAL INSTITUTION THAT CONTAINED HUNDREDS OF CHILDREN CONSIDERED TOO DISABLED TO ATTEND EVEN THE INSTITUTION SCHOOL. WE BROUGHT UNIVERSITY OF WISCONSIN STUDENTS TO THE INSTITUTION AND INVOLVED THEM IN INSTRUCTIONAL ACTIVITIES IN ANY SPACE WE COULD FIND; HALLWAYS, DAY ROOMS, STORE ROOMS AND BEDROOMS.

WHAT DID WE TEACH THESE STUDENTS? TO IMITATE AN INSTRUCTOR; TO TOUCH OBJECTS OF DIFFERENT COLORS; TO TOUCH A BODY PART IN RESPONSE TO A VERBAL CUE; TO COUNT BLOCKS IN A LINE ATTACHED TO A PIECE OF POSTER BOARD; TO PLACE A MARBLE IN, ON OR UNDER A CIGAR BOX; TO CLAP THEIR HANDS WHEN THEY REALIZED THEY WERE HAPPY ; AND, TO OPEN AND CLOSE EXTREMELY LARGE ZIPPERS ATTACHED TO PLYWOOD. WHAT ELSE CAN YOU TEACH SUCH STUDENTS ON INSTITUTION WARDS OR IN SEGREGATED SPECIAL EDUCATION CLASSES?

WE CLEARLY DEMONSTRATED WHAT MANY ALREADY KNEW: INDIVIDUALS WITH SIGNIFICANT INTELLECTUAL AND RELATED DISABILITIES COULD LEARN. AFTER MUCH FRUSTRATION, DEBATE AND INTROSPECTION WE STARTED ASKING QUESTIONS THAT DEPRESSED US. WHO CARES? DOES IT MATTER? WHY BOTHER? WHERE DOES THIS LEAD? (BROWN, NIETUPSKI & NIETUPSKI, 1976). ONCE WE STARTED TO CONSIDER THE LONGITUDINAL EFFECTS OR ULTIMATE FUNCTIONING, WE WERE FORCED TO ASK MORE POWERFUL EDUCATIONAL QUESTIONS. SPECIFICALLY, NOW THAT WE KNOW THEY CAN LEARN, WHAT SHOULD WE TEACH? WHERE SHOULD WE TEACH IT? HOW SHOULD WE TEACH? WHAT INSTRUCTIONAL MATERIALS SHOULD WE USE? WHAT PERFORMANCE CRITERIA SHOULD WE STRIVE FOR? WHAT EVALUATION STRATEGIES SHOULD WE USE? (WILLIAMS, BROWN & CERTO, 1975). SUCH QUESTIONS FORCED THE CONCLUSIONS THAT THE SKILLS WE WERE TEACHING WERE HAVING FEW, IF ANY, POSITIVE EFFECTS ON THE BASIC LIFE QUALITIES OF THE STUDENTS AND THAT THEY DESERVED MUCH BETTER.

ONE OPTION CONSIDERED WAS TO TEACH "FUNCTIONAL" SKILLS. WHY? BECAUSE WHEN WE SAID "FUNCTIONAL SKILLS" WE FELT GOOD. HOW CAN YOU FEEL GOOD ABOUT TEACHING NONFUNCTIONAL OR PREFUNCTIONAL SKILLS? HOWEVER, AS EVERYONE THINKS THEY TEACH FUNCTIONAL SKILLS WE WERE FORCED TO ADDRESS THE NEED FOR AN INSTRUCTIONALLY MEANINGFUL DEFINITION. WHILE MANY DEFINITIONS OF "FUNCTIONAL" ARE CREDIBLE, THE ONE WE AGREED TO ACTUALIZE WAS AS FOLLOWS. IF YOU ASK A PERSON WITH DISABILITIES TO DO SOMETHING AND SHE DOES NOT DO IT, SOMEONE ELSE MUST. IF NO ONE ELSE MUST DO IT, IT MAY BE IMPORTANT, BUT IT IS NOT A FUNCTIONAL SKILL IN ACCORDANCE WITH OUR DEFINITION (BROWN, ET AL., 1984). IT ASTOUNDED US TO LEARN THAT AS A RESULT OF OUR DEFINITION OF FUNCTIONAL, SPEECH AND LANGUAGE, OCCUPATIONAL, SENSORIMOTOR AND PHYSICAL THERAPISTS, PSYCHOLOGISTS, PREPACKAGED KIT SELLING AUTISM EXPERTS AND MANY OTHERS BECAME QUITE ANGRY AND ASCRIBED MANY NEGATIVE LABELS TO US.

THOSE WHO ADOPTED THE DEFINITION AND THE ASSOCIATED INSTRUCTIONAL PRACTICES STARTED TO NOTICE WONDERFUL ENHANCEMENTS. AS THE STUDENTS LEARNED FUNCTIONAL SKILLS, THEY MADE FEWER DEMANDS ON OTHERS. THEY ENJOYED MORE PRIVACY. THEY NEEDED AND WANTED LESS SUPPORT. EXPECTATIONS AND REQUIREMENTS OF THEM WERE RAISED. THEY SEEMED TO BE HAVING MORE FUN. UNIVERSITY STUDENTS IN TRAINING STARTED TO SEE RELEVANCE AND MEANING IN WHAT THEY WERE LEARNING AND DOING. TEACHER MORALE IMPROVED AND "BURNOUT" ABATED.

QUITE SOON WE REALIZED THAT CONFINING INSTRUCTION TO THE PHYSICAL PROPERTY OF SCHOOLS OR RESIDENTIAL INSTITUTIONS SEVERELY LIMITED THE NUMBER AND KIND OF LEARNABLE AND IMPORTANT FUNCTIONAL SKILLS THAT COULD BE TAUGHT AND THE ENVIRONMENTS IN WHICH THEY COULD BE PERFORMED. SEEING A STUDENT USE HIS WHEELCHAIR TO TRAVEL FROM HIS CLASSROOM TO THE RESTROOM DOWN THE HALL WAS NICE BECAUSE WE USED TO WHEEL HIM THERE MANY TIMES IN A SCHOOL DAY. HOWEVER, WOULD IT NOT BE BETTER IF HE COULD GO FROM THE GROCERY STORE TO THE RESTROOM AT THE SHOPPING MALL AND TO THE ONE IN THE MOVIE THEATRE? SEEING A STUDENT PUTTING HER COAT, HAT AND GLOVES ON PRIOR TO GOING OUT TO THE PLAYGROUND WAS NICE BECAUSE WE USED TO DO THAT FOR HER. HOWEVER, WOULD IT NOT BE BETTER IF SHE ALSO DRESSED HERSELF FOR SCHOOL AT HOME.? WE ALSO REALIZED THAT WHEN WE CONFINED INSTRUCTION TO THE PHYSICAL PROPERTY OF SCHOOLS, EVEN THE MOST CREATIVE AND INGENIOUS TEACHERS RAN OUT OF GOOD IDEAS QUICKLY. HOWEVER, WHEN WE EXPANDED THE ENVIRONMENTS USED FOR INSTRUCTIONAL PURPOSES, TEACHERS NEVER RAN OUT OF GOOD IDEAS. THEY RAN OUT OF TIME TO TEACH IMPORTANT, HELPFUL AND ENHANCING SKILLS. SOON, OUR STUDENTS WERE RIDING PUBLIC BUSES WITHOUT SOMEONE PRESENT WHO WAS PAID TO BE WITH THEM. THEY WERE ORDERING THEIR LUNCHES USING PICTURES AT FAST FOOD RESTAURANTS WITHOUT OUR ASSISTANCE. THEY WERE MAKING SANDWICHES IN THE KITCHENS OF THEIR HOMES SO THEIR PARENTS DID NOT HAVE TO DO SO. THEY WERE STOPPING THEIR WHEELCHAIRS AT CURBS AT BUSY INTERSECTIONS. WE DID NOT HAVE TO STOP THEM. THE LIST OF FUNCTIONAL SKILLS THEY WERE LEARNING AND THE INTEGRATED ENVIRONMENTS IN WHICH THEY WERE PERFORMING THEM INCREASED ALMOST DAILY (BROWN, NISBET, FORD, ET AL., 1983)

DURING THE LATE 1960'S AND EARLY 1970'S OUR STUDENTS WOULD EXIT PUBLIC SCHOOLS AND STAY AT HOME ALL DAY OR BE CONFINED TO SEGREGATED SHELTERED WORKSHOPS AND ACTIVITY CENTERS. AS THESE WERE THE "REALISTIC " POST SCHOOL OUTCOMES, WE ATTEMPTED TO PREPARE THEM FOR THEM ACCORDINGLY. THUS, AT SCHOOL WE TAUGHT THEM TO STUFF AND UNSTUFF ENVELOPES, TO FOLD AND UNFOLD INDEX CARDS, TO ASSEMBLE AND DISASSEMBLE DRAPERY HOOKS AND OTHER EXTANT SHELTERED WORKSHOP TASKS. THEN WE STARTED TO THINK "IF SHE CAN FOLD 8.5 X 11 INCH PIECES OF PAPER IN A PUBLIC SCHOOL SIMULATED WORKSHOP, SHE COULD PROBABLY LEARN TO FOLD TOWELS IN A LOCAL HOSPITAL". "IF HE CAN GO FROM POINT A TO POINT B IN HIS WHEELCHAIR BY HIMSELF AT SCHOOL, HE COULD PROBABLY LEARN TO GO FROM POINT A TO POINT B IN A GOVERNMENT BUILDING AND GATHER PAPER TO BE RECYCLED ALONG THE ROUTE. " THAT IS. WE STARTED TO CONSIDER REAL RATHER THAN FAKE , RETARDED OR PRE WORK. THE NEED TO EXPAND FROM FUNCTIONAL SKILLS TO VOCATIONAL SKILLS WAS OBVIOUS, LOGICAL AND EXCITING. WE ALSO REALIZED WE NEEDED ADDITIONAL WORDS AND DEFINITIONS TO GUIDE US.

MY FAVORITES WERE "CHAMBER OF COMMERCE WORK" AND "INTEGRATED WORK ENVIRONMENTS" . WE WANTED CHAMBER OF COMMERCE MEMBERS TO OPEN THE DOORS OF THEIR BUSINESSES AND LET US IN SO WE NEEDED A DEFINITION OF WORK THAT MADE SENSE TO THEM. WE DEFINED CHAMBER OF COMMERCE WORK AS FOLLOWS. IF A PERSON WITH A DISABILITY DOES NOT DO IT, SOMEONE ELSE MUST BE PAID TO DO IT. IF YOU DO NOT HAVE TO PAY SOMEONE ELSE TO DO IT, IT MAY BE OCCUPATIONAL THERAPY, RECREATION, SENSORY STIMULATION, ART, RETARDED WORK OR PRE WORK, BUT IT IS NOT CHAMBER OF COMMERCE WORK. INTEGRATED WORK ENVIRONMENTS WERE CONSIDERED THE SAME NATURALLY DISTRIBUTED VOCATIONAL SETTINGS IN WHICH OUR STUDENTS WOULD FUNCTION IF THEY WERE NOT DISABLED. WHEN WE TOOK THEM TO INTEGRATED WORK ENVIRONMENTS AND TAUGHT THEM TO PRODUCE CHAMBER OF COMMERCE WORK, THE RESULTS WERE WONDERFUL. SPECIFICALLY, SCHOOL PERSONNEL TAUGHT THEM TO FUNCTION EFFECTIVELY IN INTEGRATED VOCATIONAL SETTINGS (AUTHENTIC INSTRUCTION) AND ADULT SERVICE AGENCY PERSONNEL ARRANGED FOR THEM TO CONTINUE TO FUNCTION THEREIN AFTER SCHOOL EXIT (BROWN, 2005; BROWN, SHIRAGA & KESSLER, 2006). WHEN WE LOOK BACK OVER THE LAST FORTY YEARS WE SEE THAT IT HAS BEEN DEMONSTRATED MANY TIMES IN MANY PLACES BY MANY PEOPLE THAT INDIVIDUALS WITH SIGNIFICANT INTELLECTUAL AND RELATED DISABILITIES CAN BE TAUGHT TO PERFORM REAL WORK IN INTEGRATED VOCATIONAL SETTINGS (CERTO ET AL., IN PREPARATION).

NOW THEY ARE SUCCEEDING IN THE REAL WORLD OF WORK LONGER THAN MOST IMAGINED WAS FEASIBLE, BUT AS THEY AGE THEY ARE LOSING INTELLECTUAL AND PHYSICAL FUNCTIONS FASTER THAN THEIR PEERS WITHOUT DISABILITIES. EACH YEAR MORE EXPERIENCE CIRCUMSTANCES SIMILAR TO THOSE OF THE TWO INDIVIDUALS ON THE NAVAJO RESERVATION WHO STAY AT HOME WITH THEIR MOTHER. THAT IS, PERFORMING REAL WORK IN THE REAL WORLD WILL BE TAKEN OUT OF THE EQUATION. WHO WILL BE WITH THEM IF THEY RETIRE OR OTHERWISE CANNOT OR DO NOT WORK? WHAT WILL THEY DO ALL DAY?

NOW LET US RETURN TO THE NATIVE AMERICAN WOMAN AT THE TASH CONFERENCE. I COMMUNICATED TO HER THAT IF WE TAKE ENTERPRISE OUT OF THE SYSTEM, WE ARE LEFT WITH AT

LEAST TWO MAJOR OPTIONS. FIRST, WE COULD FOCUS ON THE DEVELOPMENT OF FUNCTIONAL SKILL REPERTOIRES. THAT IS, WE COULD TEACH THE TWO INDIVIDUALS TO DO AS MUCH AS POSSIBLE FOR THEMSELVES IN THE ENVIRONMENTS IN WHICH THEY COULD REASONABLY FUNCTION. WHENEVER THEY LEARN TO DO SOMETHING THAT IN THE PAST SOMEONE ELSE DID FOR OR TO THEM, THEY ARE REDUCING THE PRESSURES ON OTHERS, THEY ARE EXPERIENCING MORE PRIVACY AND PERSONAL CHOICE, ETC. MOST OF US APPRECIATE THE IMPORTANCE OF THIS BECAUSE WE KNOW WE WILL LOSE FUNCTION AND FEAR AND RESENT THE DAY OTHERS WILL DO FOR US WHAT WE ONCE DID FOR OURSELVES. SECONDLY, IF THEY COULD BE TAUGHT TO AT LEAST PARTIALLY PARTICIPATE IN THE PREPARATION OF THEIR FOOD, IN THE CLEANING OF THEIR CLOTHES, IN THE MAINTANENCE OF THEIR RESIDENCES, IN THE CARE OF THEIR BODIES, ETC, MAYBE THEY CAN BE TAUGHT TO USE THOSE SKILLS TO HELP OTHERS ON THE RESERVATION WHO NEED ASSISTANCE IN THESE AND SIMILAR TASKS (BAUMGART, ET AL, 1980). SHE LOOKED IN MY EYES, SMILED AND SAID THANK YOU.

MY FIRST CHOICE IS ALMOST ALWAYS REAL WORK IN THE REAL WORLD. SOME GET THE INSTRUCTION AND SUPPORT NEEDED TO DO IT. IT IS WAY PAST THE TIME WHEN INTEGRATED WORK OPTIONS SHOULD BE AVAILABLE TO ALL. HOWEVER, WHEN I FIRST HEARD OF THE SITUATION ABOVE, I THOUGHT IT WAS SPECIFIC TO THE LOCAL NAVAJO RESERVATION. I REALIZE NOW THAT THE SAME PHENOMENA ARE EXPERIENCED BY MANY INDIVIDUALS WITH AND WITHOUT DISABILITIES AND THEIR FAMILY MEMBERS EVERYWHERE. LEARNING TO DO AS MUCH AS YOU CAN FOR YOURSELF AND THEN USING WHAT YOU HAVE LEARNED TO HELP OTHERS IS A GOOD WAY TO GO THROUGH LIFE.

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