GET TO THE CORE OF IT: INTEGRATING CIL CORE SERVICES FOR A HOLISTIC CONSUMER EXPERIENCE

CONNECTING IL PHILOSOPHY AND SEAMLESS CONSUMER-DRIVEN SERVICE DELIVERY

PRESENTERS: BRUCE DARLING AND KIMBERLY TISSOT

BRUCE DARLING: I GET THE EXCITING OPPORTUNITY TO TALK TO YOU ABOUT

IL HISTORY AND PHILOSOPHY.

SO, FIRST IN MY YEARS OF EXPERIENCE WHAT I HAVE SEEN AT TIMES

IS THERE IS A LOT OF INTERPRETATION OVER WHAT THE IL PHILOSOPHY

IS AND WHAT CONSUMER CONTROL IS.

AND I HAVE SEEN AMAZING EXAMPLES OF INCREDIBLE EMPOWERMENT

THAT HAS HAPPENED, AND THEN I HAVE SEEN OTHER GROUPS USE THESE

TERMS AND THIS PHILOSOPHY AS A WEAPON.

SO, MY FIRST EXPERIENCE WITH A DEAR FRIEND OF MINE WAS SHE

HAD BEEN WORKING WITH THE DEVELOPMENTAL DISABILITY AGENCY AND

SHE MOVED IN TO WHAT THEY CALLED A NONCERTIFIED INDIVIDUAL

RESIDENTIAL ALTERNATIVE WHICH IS BASICALLY A SHARED LIVING

SITUATION WITH SOME OTHER WOMEN. AND I WON'T GO INTO ALL THE

DETAILS ON IT, BUT BASICALLY THIS THREE WOMEN IN A HOUSE

ROOMMATE SITUATION FELL APART.

AND HERE SHE WAS A WOMAN WITH SSI WHO HAD THE MONTHLY RENTFOR A THREE BEDROOM HOUSE IN THE SUBURBS OF ROCHESTER WITH

ELECTRIC HEAT IN THE WINTER.

CAME TO US AND SAID I CAN'T PAY MY BILLS AND SHE WAS VERY

WORRIED ABOUT THIS. AND I LOOKED AT THIS AND I SAID HONEY NO

ONE COULD PAY THESE BILLS WITH THAT INCOME. THIS DOESN'T WORK.

WHEN WE CALLED THE AGENCY, THEY SAID WELL THIS IS INDEPENDENT

LIVING. THIS WAS HER CHOICE.

SO, I WANT YOU TO HAVE A SENSE OF SHE WAS BASICALLY SET UP

WITH A SITUATION TO FAIL. AND WHEN THE AGENCY DIDN'T DO THEIR

DUE DILIGENCE AND THEIR WORK, THEY BASICALLY PUSHED IT ALL OFF

ON HER CALLING IT INDEPENDENT LIVING. SO, I HAD SOME THINGS THAT

I SAID THAT WERE PROBABLY NOT POLITE. THIS WAS NOT INDEPENDENT

LIVING. WHEN YOU MAKE CHOICES, INFORMED CHOICE IS WHAT WE ARE

TALKING ABOUT AND PEOPLE NEED TO BE GIVEN INFORMATION AND

OPTIONS AND THAT CLEARLY WASN'T WHAT THEY WERE DOING.

IT IS NOT JUST OTHER AGENCIES. I HAVE HEARD FROM CENTERSFOR INDEPENDENT LIVING, WE DON'T SERVE ANYONE WHO USES DRUGS OR

ALCOHOL. TO WHICH I RESPONDED, I AM NOT SURE I COULD HAVE A

STAFF IF THAT WERE THE CRITERIA. AND THEN -- OKAY. I KNOW THIS

IS BEING RECORDED BUT (I CAN'T HEAR).

AND THEN THE OTHER ONE I HEARD WAS HE IS IN A NURSING FACILITY

AND IF HE WANTS TO GET OUT REALLY, HE CAN JUST GET OUT OF BED AND

COME OVER TO THE CENTER. HE WAS THE FOUNDING BOARD PRESIDENT

AND HE IS RIGHT NEXT DOOR IN THE NURSING FACILITY. WE ARE NOT

GOING TO GO OVER THERE AND TALK TO HIM. OKAY. WHAT? SO, I WANT

TO UNDERSTAND THE SENSE OF WHILE THERE IS THIS MAY SEEM LIKE IT

IS OLD NEWS AND HISTORY IS OLD, LESS OLD FOR SOME OF US. BUT

ALTHOUGH THIS SEEMS LIKE IT IS OLD STUFF, WE DO NEED TO REVISIT

IT AND IT DOES UNDER PIN WHAT WE ARE GOING TO TALK ABOUT.

WHAT ABOUT LANGUAGE? SO, WITHIN THE DISABILITY COMMUNITY RIGHT NOW.

EVERYONE IS FAMILIAR WITH PERSON FIRST LANGUAGE. I AM A PERSON

WITH A DISABILITY AND WE HAVE FOR I DON'T KNOW HOW MANY YEARS. AS LONG

AS I CAN REMEMBER REALLY REINFORCED FOR FOLKS USE PERSON FIRST

LANGUAGE. IT HAS BEEN OUR MANTRA. AND WHY DO WE NEED TO DO THAT?

WE NEEDED TO DO THAT BECAUSE FRANKLY THE OUTSIDE WORLD DIDN'T

RECOGNIZE WE WERE PEOPLE.

SO, WE NEEDED -- ALL OF OUR LANGUAGE WAS DEFINED AROUND ALL

RIGHT. HELLO. I AM A PERSON WITH A DISABILITY. JUST BECAUSE

THE NONDISABLED PEOPLE WELL THEY MADE FUN OF US AS PATIENTS OR

SICK PEOPLE OR OBJECTS OR RECIPIENTS OF CARE OR WHATEVER THEIR

FRAMING WAS. THEY FAILED TO RECOGNIZE THAT WE WERE ACTUALLY PEOPLE WHO

WANTED TO HAVE LIVES. WHAT IS HAPPENED OVER THE LAST COUPLE OF YEARS

IS THAT IDENTITY FIRST LANGUAGE HAS BEGUN TO CROP UP. THERE IS A

QUESTION AROUND AM A PERSON WITH A DISABILITY OR AM A DISABLED

PERSON? AND THIS HAS COME MOST CLEARLY ARTICULATED FROM

AUTISTICS WHO HAVE SAID AS DIVERSE INDIVIDUALS. YOU CAN'T

SEPARATE MY DISABILITY FROM WHO I AM. SO, TO SAY I AM A PERSON

WITH A DISABILITY DOESN'T ACTUALLY COVER IT. AND I CONSIDER

MYSELF NEURO ATYPICAL. SO, LIKE ANYONE WHO KNOWS ME CAN

PROBABLY FIGURE THAT OUT IN AROUND 47 SECONDS.

BUT SO, YOU CAN'T REALLY -- AS I THOUGHT ABOUT IT -- YOU

CAN'T SEPARATE OUT THAT FROM WHO I AM. IT IS ESSENTIALLY -- IT

IS A PART OF WHO I AM. IF I DIDN'T HAVE IT, SOME DAYS LET ME

ASSURE YOU. I WISH I WERE JUST A TAD BIT MORE LINEAR AND A

LITTLE MORE FOCUSED AS I GO FROM THE FIRST FLOOR TO THE SECOND

FLOOR FORGET WHAT I WANT. GO DOWN TO THE FIRST FLOOR AND DO

THIS ABOUT THE SIXTH TIME I AM LIKE REALLY FOR GOD SAKES COULD

YOU JUST BE A LITTLE MORE LINEAR OR WRITE A NOTE TO GET TO THE

SECOND FLOOR. IT GETS REALLY FRUSTRATING SOMETIMES BUT I THINK

TO MYSELF WHAT WOULD I GIVE UP IF I DIDN'T HAVE THIS KIND OF

RANDOMNESS IN MY HEAD? IT GIVES ME ALL SORTS OF GIFTS IN THINGS

THAT I WOULDN'T OTHERWISE HAVE. I THINK OF THINGS IN WAYS OTHER

PEOPLE DON'T. I SEE THIS AS A BENEFIT. I WANT TO HIGHLIGHT THAT

THIS LANGUAGE ISSUE AROUND PERSON FIRST WHICH WAS CREATED FOR

THE OUTSIDE WORLD TO GET THEM TO UNDERSTAND THAT WE ARE PEOPLE

HAS EVOLVED INTO A GREATER DIVERSITY OF LANGUAGE WHICH INCLUDES

PERSON FIRST LANGUAGE. AND FRANKLY YOU WILL SEE SOME OF THIS

STUFF COMING FROM ADAPT. I LIKE THE LANGUAGE OF DISABLED

AMERICANS. IT HAS A STRENGTH TO THAT TERM. AND TRUTHFULLY AS

SOMEONE WHO WRITES A PERSON WITH DISABILITY, PERSON WITH A

DISABILITY EVERY SO OFTEN YOU JUST WANT TO THROW A DISABLED

PERSON IN THERE JUST TO MIX IT UP A LITTLE BIT BUT THERE IS

SOMETHING MUCH MORE BASIC GOING ON IN TERMS OF LANGUAGE IS MORE

FLUID. I SPEND A LOT OF TIME ON THIS UPFRONT BECAUSE YOU

WOULDN'T BELIEVE THE PEOPLE THAT ARE NOT NECESSARILY AWARE OFTHESE CONVERSATIONS SORT OF WILL JUMP ALL OVER YOUR SHIT WHEN

YOU START USING IDENTITY FIRST LANGUAGE AND THEY DON'T RECOGNIZE

THAT'S WHAT IS GOING ON. ANY QUESTIONS ON THAT OR THOUGHTS?

AUDIENCE: WE HAVE HAD SOME DISCUSSIONS WITH NEWER STAFF

AND NEWER STAFF THAT ARE YOUNGER AND ALSO HAVE DISABILITIES

WHERE THEY OBJECT TO THE TERM CRIP. I DON'T KNOW IF YOU WANT TO

GO INTO THAT OR WHAT. IT IS KIND OF AN INTERESTING THING THAT

WE HAVE EXPERIENCED IN OUR AGENCY ABOUT THAT TERM.

BRUCE: WHAT I THINK IS EXCITING RIGHT NOW IS THAT

THERE IS MORE -- LIKE IT USED TO BE THIS SORT OF RIGID ORTHODOXY WHERE WE

ARE ALL PERSONS WITH DISABILITIES. AND THERE WAS SOME OF THESE

OTHER TERMS YOU GET TO PUT IN THAT PEOPLE WERE RECLAIMING. CRIP WAS

RECLAIMED IN A WAY. SAME WAY I SELF IDENTIFY AS QUEER. IT IS

NOT THE 20 SOMETHING QUEER IT IS MORE THE 50 SOMETHING RECLAIMED

QUEER. WHICH REALLY OH, MY GOD, IT IS VERY COMPLICATED.

BUT THE THING THAT'S EXCITING IS THIS CONVERSATION ABOUT

LANGUAGE IS ACTUALLY A CONVERSATION ABOUT IDENTITY AND WHO WE

ARE, AND IT IS REALLY EXCITING. AND I FEEL LIKE SOME OF THIS

LANGUAGE ABOUT DIFFERENTIATING OURSELVES FROM THE NONDISABLED

OVERLORDS IS REALLY A GOOD THING. MY STAFF GETS STRESSED WHEN

I SAY THAT. NO OFFENSE TO NONDISABLED PEOPLE IN THE ROOM. THE

SEPARATION IS IMPORTANT BECAUSE IT BUILDS BEYOND THAT QUESTIONS

OF IDENTITY BUILD INTO COMMUNITY AND THAT UNDERPINS A LOT OF

WHAT WE ARE TRYING TO DO IN OUR CENTERS. I WOULD LOVE TO CHAT

ABOUT THE CRIP ISSUE LATER.

MOVING ON. SPECIAL NEEDS.

WE DON'T USE THAT. I REALLY DON'T USE PEOPLE WITH SPECIAL

ABILITIES BECAUSE THAT'S LIKE LYING. AND EUPHEMISMS – LIKE DIFFERENTLY

ABLED. LISTEN TO THE COMMUNITY. I KNOW THERE IS GOING TO BE SOME

VARIATION IN LANGUAGE. I TEND TO BE A LITTLE MORE AGNOSTIC ABOUT HOW

PEOPLE SELF IDENTIFY. THAT IS THEIR INDIVIDUAL CHOICE, BUT HONESTLY

SOME OF THE WORDING IS A LITTLE WEIRD.

AMINA DONNA KRUCK: THIS IS A COMMENT ABOUT THAT. THE THING IS IF YOU

WANT TO WORK WITH PARENTS, YOU HAVE TO RELAX ABOUT THE WORD

SPECIAL, BECAUSE THEY ARE VERY COMMITTED TO HAVING SPECIAL KIDS.

AND SO, AS WE ARE DOING YOUTH OUTREACH, WE JUST HAVE TO BE

SENSITIVE TO THAT, THAT THAT'S LIKE THEY ARE FROM ARIZONA AND I

AM FROM MONTANA AND THEY HAVE THEIR WAYS. YOU KNOW WHAT I MEAN?

SO OVER TIME YOU MIGHT BE ABLE TO BRING THEM ALONG BUT JUST BE

AWARE.

BRUCE: AND HONESTLY, I AM NOT GOING TO GET INTO A FIGHT WITH

SOMEONE ABOUT HOW THEY SELF IDENTIFY IN ORDER TO MEET THEIR

NEEDS. I THINK THE LGBTQ COMMUNITY AND AIDS COMMUNITY REALLY

GOT THIS. OK, IF YOU ARE A MAN HAVING SEX WITH MEN,

HELLO, WAKE UP. BUT THE LBGTQ COMMUNITY THAT'S MY PERSONAL

OPINION. BUT WE RECOGNIZE THAT YOU DON'T HAVE TO SAY THE WORDS

TO GET THE SERVICES AND SUPPORTS YOU NEED. I FEEL IT IS VERY

SIMILAR WITH ELDERLY INDIVIDUALS. DO YOU HAVE TO SAY I AM

DISABLED IN ORDER TO GET SERVICES FROM OUR CENTER, ABSOLUTELY

NOT. SO, I THINK THE VARIATION LANGUAGE IS FINE. SO, TALKING A

LITTLE BIT ABOUT THE HISTORY BECAUSE THAT'S SORT OF FRAMES WHO

WE ARE. OUR MOVEMENT ACTUALLY CAME OUT OF AND WAS INFORMED BY AND

I PUT IT IN THE FIRST -- CIVIL RIGHTS. THE CIVIL RIGHTS

MOVEMENT IN THE SIXTIES AND SEVENTIES.

PEOPLE ARE FAMILIAR WITH THAT. THE INSTITUTIONALIZATION

THE EFFORT TO GET FOLKS OUT OF INSTITUTIONS, DE-MEDICALIZATION

BACK IN THE DAY. THE SELF-HELP MOVEMENT WHERE PEOPLE WERE HELPING

THEMSELVES. AA BEING THE BEST EXAMPLE OF THAT AND THE CONSUMER

MOVEMENT WITH RALPH NADER. ALL OF THOSE UNDERPIN THE WORK THAT WE ARE

DOING. I WANTED TO HIGHLIGHT TWO LEADERS FROM THE MOVEMENT ED

ROBERTS FROM CALIFORNIA AND BERKELEY. HE HAD POLIO. SO, FOR FOLKS

WHO ARE NOT FAMILIAR WITH HIM, LOOK HIM UP. HE HAD POLIO. HE

HAD A VERY POWERFUL MOTHER WHO MADE SURE HE WENT TO SCHOOL WITH OTHER

KIDS. I WANT TO HIGHLIGHT THAT PEOPLE'S MOTHERS ACTUALLY DO

MAKE A BIG DIFFERENCE. I CREDIT MY MOTHER FOR A LOT.

AND THAT HE ENDED UP LEADING THE CENTER

IN BERKELEY AS A PERSON WHO HAD A VERY SIGNIFICANT DISABILITY.

THE OTHER LEADER I WANT TO HIGHLIGHT IS WADE BLANK. HE WAS THE

FOUNDER OF THE ATLANTIS COMMUNITY. HE DOESN'T GET AS MUCH

ATTENTION IN THE IL MOVEMENT, IN PART BECAUSE HE WAS A MINISTER

AND SOCIAL WORKER IN A NURSING FACILITY, SO WE TEND NOT TO THINK

ABOUT THOSE PEOPLE -- SOCIAL WORKERS IN NURSING FACILITIES -- AS BEING

WHO HELPED START OUR MOVEMENT. BUT WHAT HE DID IN THAT

FACILITY WAS IN WORKING WITH YOUNG PEOPLE, HE DE-INSTITUTIONALIZED

THEM INTO THE COMMUNITY AND THAT BECAME THE

ATLANTIS COMMUNITY IN DENVER AND THEY STARTED THE GROUNDWORK FOR

ADAPT. SO, FROM ED ROBERTS I AM TAKING PEOPLE WITH SIGNIFICANT

DISABILITIES AND THE LEAD IN OUR MOVEMENT -- THAT WHOLE PEER SUPPORT,

EDUCATION, IL SKILLS TRAINING PIECE. FROM WADE IT WAS REALLY THE

ACTIVIST AND COMMUNITY INTEGRATION PIECE. THIS DOESN'T MEAN THESE

ARE THE ONLY TWO LEADERS. LOCALLY I TALK ABOUT CARMEN HERNANDEZ. SHE

WAS A WOMAN WHO HAD MUSCULAR DYSTROPHY AND ACTUALLY TERRORIZED THE

ENTIRE CITY OF ROCHESTER WHEN SHE DECIDED TO HAVE A BABY. THEY

COULDN'T FIGURE OUT HOW DOES A WOMAN WHO COULD ONLY MOVE HER ONE FINGER

HAVE A BABY AND RAISE A CHILD. SHE REALLY PUSHED THOSE LIMITS. SO, I

THINK WHEN WE ARE TALKING ABOUT WHO OUR LEADERS ARE, IT IS

IMPORTANT LOCALLY TO SHARE WHO YOUR LOCAL LEADERS ARE WHEN YOU

ARE DOING THIS TRAINING. THE INDEPENDENT LIVING MOVEMENT IS A NEW

PARADIGM WITH DISABILITY RIGHTS, CULTURE, AND PRIDE AS OPPOSED TO THE

MEDICAL, REHAB AND CHARITY MODEL.

SO, WE ARE GOING TO QUICKLY GO THROUGH. ARE YOU ALL FAMILIAR

WITH THIS? YOU HAVE ALL DONE THIS. THIS WAS MY FIRST DAY IN IL.

I WAS TO READ A BOOK AND TO RESEARCH THE ORIGINAL WRITING ON THIS

COMPARING THE IL MODEL TO THE REHAB MEDICAL MODEL. OKAY I AM

GOING TO CONFESS THAT THAT WAS SILLY. I DIDN’T QUITE GET IT.

I AM NOT A GOOD READER. DEFINITION OF THE PROBLEM LET'S

START THERE. IN THE MEDICAL MODEL WHAT IS THE PROBLEM?

AUDIENCE: WE ARE.

BRUCE: WHO WAS THAT? WE ARE SUPPOSED TO USE THE MICROPHONE.

SO, DEFINITION OF THE PROBLEM IN IL. THE ENVIRONMENT.

I’M SORRY I APOLOGIZE. TALK.

AUDIENCE: I WAS GOING TO SAY THE COMMUNITY AT LARGE.

BRUCE: AND FOR THEM IT IS OUR IMPAIRMENT THAT'S THE

PROBLEM. IN THE INDEPENDENT LIVING MODEL, IT CAN BE DEPENDENCE;

IT CAN BE THE ENVIRONMENT; IT CAN BE THE LACK OF LEGAL PROTECTIONS

AND RIGHTS IN SOCIETY. SO, THAT'S A GREAT ADDITION THERE. WHERE IS THE

PROBLEM LOCATED? THE LOCUS OF THE PROBLEM IS FOR THE MEDICAL

MODEL? IT IS US. IT IS US. IT IS IN ME. IT IS NOT THAT.

WITHIN THE IL MODEL, THE LOCUS OF THE PROBLEM IS SOCIETY.

SO, WHEN I AM BEHAVING IN A WAY IN CLASS THAT'S NOT WHAT IS

CONSIDERED SOCIALLY ACCEPTABLE, I AM THE PROBLEM. IT IS NOT THAT

THE TEACHER IS NOT TEACHING TO ME. IT IS ME THAT'S THE PROBLEM.

SO THAT'S THE LOCUS. THE SOLUTION TO THE PROBLEM IS TREATMENT.

THEY WANT TO FIX US. THIS IS IN THE MEDICAL MODEL. THIS IS

IMPORTANT, BECAUSE HONESTLY AT THE END OF THE DAY, I THINK THE

CRUX OF WHAT WE ARE DEALING WITH IS THAT SOCIETY AT LARGE SEES US

AS BROKEN VERSIONS OF THEM AND NOT UNIQUE VERSIONS OF OURSELVES.

THAT REALLY UNDERSCORES A LOT OF WHAT IS GOING ON.

IN THE INDEPENDENT LIVING MODEL, WE FOCUS ON ADVOCACY BARRIER REMOVAL,

CONSUMER CONTROL, WHICH IS INCREDIBLY IMPORTANT FOR US IN

INDEPENDENT LIVING. PEER SUPPORT. ALL OF THOSE OTHER PIECES THERE.

SO HOW THESE PLAY OUT -- THESE FIRST THREE, I GOT A CALL ONE

DAY FROM A NURSE. THANK YOU. I GOT A CALL ONE DAY FROM A NURSE

WHO -- THIS IS HOW SHE STARTED THE CALL. I AM NURSE RATCHET AND I

AM WORKING WITH ONE OF YOUR CONSUMERS. I WANT TO KNOW FIRST, ARE

YOU A PROFESSIONAL, OR ARE YOU ANOTHER PERSON WITH A DISABILITY?

I WAS LIKE WOW. I HAPPEN TO BE A PROFESSIONAL WHO HAS A

DISABILITY AND I CAN'T IMAGINE THAT ANY OF THE DISABLED PEOPLE

YOU SPOKE TO BEFORE ME WASN'T PROFESSIONAL, SO I AM NOT QUITE

SURE WHERE THEIR CONVERSATION IS GOING. BUT IT REALLY CAME DOWN

TO AN ISSUE WHERE WE WERE WORKING WITH SOMEONE WHO HAD JUST

STARTED A JOB AND WAS TIRED FROM WORKING, WHICH IS WHAT HAPPENS

WHEN YOU WORK A LOT. AND HE WOULD GET HOME AND WOULDN'T MAKE THE

TRANSFER TO HIS BED. HE WOULD PULL HIS SHEETS FROM THE BED AND

SLEEP ON THE CONCRETE FLOOR EVERY NIGHT.

THIS IS NOT A SITUATION FOR A GOOD JOB. SO, WE HELPED GET

HIM A CEILING LIFT THAT HE COULD USE INDEPENDENTLY. SHE WAS

HORRIFIED. THIS WAS -- WHAT HE NEEDED WAS CONSTANT PHYSICAL

THERAPY AND TO DO ALL OF THESE TRANSFERS HIMSELF TO MAINTAIN HIS

PHYSICAL ABILITY. BECAUSE SHE SAW THE PROBLEM AS BEING HIS

PHYSICAL -- WE WERE LOOKING AT THIS AS HE IS TIRED. HE HAS A

JOB AND HE WANTS TO SUCCEED AT THAT. THIS IS A PIECE OF

EQUIPMENT THAT WILL SOLVE THE PROBLEM. THIS PLAYS OUT IN VERY

REAL WAYS IN THOSE DISAGREEMENTS AND BEING ABLE TO IDENTIFY THAT

AS HELPFUL.

SOCIAL ROLE. OKAY. SO, WE ARE VERY CLEAR. SOCIAL ROLE IN

THE MEDICAL MODEL IS WE ARE THE PATIENT OR THE SICK PERSON, THE

CLIENT. WE ARE RECIPIENTS OF CHARITY. IN THE INDEPENDENT

LIVING MODEL, WE ARE CUSTOMERS. WE TALKED ABOUT THE CONSUMER

MOVEMENT. WE ARE CHOOSING THESE SERVICES. WE ARE THE CUSTOMER.

YOU SHOULD BE PROVIDING US WITH GOOD SERVICE. YES?

AUDIENCE: I HAVE BEEN WONDERING FOR SOME TIME WHY WE

CALL CONSUMERS CONSUMERS AND NOT CUSTOMERS.

BRUCE: HONESTLY THAT LANGUAGE PREDATES ME. WE TEND

TO -- I AM AGNOSTIC AND LET PEOPLE MAKE CHOICES. WE TEND TO SAY

PARTICIPANTS. IT DEPENDS ON WHERE. BUT THE LANGUAGE OF THE

COMMUNITY HAS TYPICALLY BEEN CONSUMER. BUT IT IS I THINK OPEN.

I THINK WE ARE AT A POINT NOW WHERE WE ARE BEGINNING TO HAVE

SOME OF THESE CONVERSATION. I THINK THAT'S ACTUALLY AN EXCITING

THING FOR US AS A COLLECTIVE TO EXPLORE.

AND THEN WHO CONTROLS? I THINK FOR US, THE MEDICAL MODEL,

THE PROFESSIONALS CONTROL. THE INDEPENDENT LIVING MODEL, THE

PERSON WITH DISABILITY OR SOMEONE OF THEIR CHOOSING CONTROLS. REALITY

CHECK YOU CAN HAVE MEDICAL PROFESSIONALS WHO REALIZE THEY ARE

NOT IN CONTROL. MY DOCTOR IS A GOOD EXAMPLE. I WAS JUST AT THE

DOCTOR'S APPOINTMENT AND HE SAID, SO BRUCE, DID WE MAKE ANY MED

CHANGES THIS ROUND? ACKNOWLEDGING I AM A LITTLE CREATIVE AND I

ACTUALLY TAKE A LOT OF MEDS AND I WILL MIX AND MATCH AND CHANGE

THEM TO TRY TO FIND JUST THE RIGHT MIX AND I DON'T ALWAYS KEEP HIM UP TO

DATE ON THE CHANGES. ALTHOUGH HE HAS THE POWER TO PRESCRIBE THE

MEDICATIONS, I HAVE THE CONTROL OVER WHAT GOES INTO MY MOUTH. HE IS

ACTUALLY PRETTY GOOD ABOUT THAT. SOMETIMES IN CENTERS FOR INDEPENDENT

LIVING WHEN THE PUSH IS TO GET THINGS DONE, IT WOULD JUST

BE EASIER JUST TO TELL PEOPLE HERE IS WHAT YOU NEED TO DO. WE

ALL HAVE BEEN AT THAT POINT WHERE IT IS BUSY. IT IS THE END OF

THE DAY. WE JUST NEED TO GET THIS DONE, AND YOU WANT TO GO

THERE. IT IS REALLY IMPORTANT THAT WE NOT DO THAT.

BECAUSE THE PERSON IS IN CONTROL. IT DOES TAKE A LITTLE

MORE WORK, BUT IT IS IMPORTANT PART OF WHO WE ARE.

THE DESIRED OUTCOME. I TALKED ABOUT THE GENTLEMAN WITH THE

CEILING LIFT. HIS DESIRED OUTCOME WAS GAINFUL EMPLOYMENT, WHICH

HE WAS VERY SUCCESSFUL AT AFTER HE COULD SLEEP THROUGH THE NIGHT

WITHOUT BEING ON THE FLOOR. MAXIMUM SELF CARE. WE ALL HAVE HEARD ABOUT

THE QUAD WITH THE QUAD KNOBS WHO DECIDED TO PUSH HIMSELF DOWN THE HALL.

I HAD A FRIEND WHO LIVED LIKE THAT UNTIL HE REALIZED HE WOULD BE MORE

LIKELY TO PICK UP PEOPLE IF HE WERE QUICKER IN GETTING TO THE BREAK ROOM.

I CAN'T SAY THAT HIS MOTIVATION WAS GOOD, BUT THE OUTCOME WAS.

AND SOCIAL ACCEPTABILITY. THERE IS A WHOLE EFFORT TO MAKE US LOOK

LIKE THEM.

SO, FOR EXAMPLE AT OUR CENTER, WE HAVE FOLKS WHO -- THERE IS A

LOT OF -- WE HAVE SOMEONE WITH A GREMLIN. YOU KNOW A PLASTIC

GREMMIE FROM GREMLINS. SOME PLACES TRY TO ACTUALLY TAKE THIS

STUFF AWAY FROM PEOPLE AND TELL THEM -- THERE WAS ANOTHER

GENTLEMAN WHO CARRIED AROUND A TWIDDLE STICK. IT WAS A THING

THAT HE JUST TWIDDLED. IT MADE HIM COMFORTABLE. IT HELPED HIM MANAGE

IN THE WORLD. THE GREMLIN IS ACTUALLY A GREAT COMMUNICATION TOOL. BUT

OTHER PEOPLE TRIED TO NORMALIZE US AND MAKE US MORE SOCIALLY

ACCEPTABLE AND TRY TO TAKE THESE THINGS AWAY FROM US. WHEN YOU

COME TO OUR CENTER I THINK WE ACTUALLY DO THE EXACT OPPOSITE.

WE HAVE EMBRACED THIS GREMLIN AND THERE IS A VIDEO OF ME TALKING TO

THE GREMLIN AS IF IT IS AN ACTUAL PERSON. IT IS DISTURBING.

THE THING -- IS I THINK ONE OF THE THINGS WE HAVE TO REMEMBER IS

THIS SENSE OF WE ARE GOING TO MAKE YOU LIKE US AS A SOCIETAL

PRESSURE THAT THE MEDICAL MODEL WANTS US TO BUY INTO. WE WANT

INDEPENDENT CONTROL. WE MAY NOT BE ABLE TO PHYSICALLY DO IT

OURSELVES. WE WANT PRIDE AND A POSITIVE DISABILITY IDENTITY. THAT'S

NOT NECESSARILY EASY EITHER, BECAUSE WHEN WE ARE TALKING ABOUT

PRIDE IN DISABILITY, PEOPLE DON'T NECESSARILY GET THAT. SO, I

HAD A DEAR FRIEND WHO SAID, YOU KNOW, YOU TALK ABOUT BEING PROUD

AS A NEURO ATYPICAL PERSON. IT IS A PATHOLOGY. IT IS IN THE DSL

AS A DIAGNOSIS. AND MY RESPONSE WAS, WELL SWEETIE, YOU ARE GAY.

HOMOSEXUALITY WAS IN THERE UNTIL THE MID '70S. IT IS TAKING

LONGER FOR THEM TO CATCH UP WITH US AND RECOGNIZE THE NEURO DIVERSITY.

JUST BECAUSE YOU HAVE A DIAGNOSIS – AS I SAID, THESE THINGS MAKE

US WHO WE ARE.

OUR LIVED EXPERIENCES MAKES US WHO WE ARE AND IT IS SOMETHING WE

SHOULD BE PROUD OF. IT ADDS TO OUR EXPERIENCE AND WE NEED TO

REINFORCE THAT MESSAGE TO THE FOLKS WHO ARE COMING INTO OUR CENTERS.

BECAUSE FRANKLY, ALL OF THE SAME RULES THAT WE HAVE AND WE HAVE

BEEN TOLD THAT WE WERE WRONG; THESE ARE THE THINGS -- YOU HAVE TO

BE FIXED. YOU ARE THE PROBLEM. THOSE ARE THE THINGS THAT THEY

ARE COMING IN WITH AS WELL. AND WE NEED TO BE A PLACE WHERE

THEY CAN HEAR, YOU KNOW WHAT, THIS IS NOT -- YOU ARE NOT THE

PROBLEM. THE WORLD IS.

SO, ALL OF THESE TIE TOGETHER AND ACTUALLY THE CORE SERVICES

WERE SET UP TO OPERATIONALIZE THIS PHILOSOPHY. SO, WHETHER YOU

ARE CONNECTING WITH PEOPLE THROUGH INFORMATION AND REFERRAL,

WHETHER YOU ARE DOING PEER SUPPORT. THE QUESTION ABOUT SUPPORT

GROUPS IS REALLY INTERESTING. THERE ARE LOTS OF DIFFERENT WAYS

TO PROVIDE PEER SUPPORT AND SUPPORT GROUPS ARE A REALLY POWERFUL

TOOL TO DO THAT. BUT THERE IS PEER COUNSELING, PEER MENTORING.

INDEPENDENT LIVING SKILLS TRAINING. AGAIN, WHETHER IT IS A GROUP

KIND OF PROCESS OR INDIVIDUALIZED INDEPENDENT LIVING SKILLS TRAINING,

THAT'S THE KIND OF THING THAT CENTERS CAN DO.

AND TRUTHFULLY USING THOSE PIECES TOGETHER – NO ONE HELPS DISABLED

PEOPLE UNDERSTAND HOW TO LIVE WITH A DISABILITY LIKE OTHER DISABLED

PEOPLE. I AM DIABETIC.

IT WAS THE -- I HAVE TO SAY THE MOST HELPFUL PEOPLE WERE OTHER

DIABETICS WHO SAID DO NOT EAT THE SUGAR FREE CANDY.

TRUST ME. YOU WILL UNDERSTAND. FOR ME, HONESTLY, ONE OF THE

MOST EXCITING TRAININGS I WENT TO WAS FROM A NURSE WHO HERSELF

WAS DIABETIC AND SHE WAS TRAINING OTHER NURSES AND MEDICAL

PROFESSIONALS AND SHE STARTED WITH I WAS A DIABETES EDUCATOR

FOR 20 YEARS AND THEN I GOT DIABETES. AND I REALIZED THAT FOR

20 YEARS, I HAD SPUN CRAP AND TOLD PEOPLE THINGS THAT WERE NOT

GOING TO WORK IN REAL LIFE.

SHE SAID, UNFORTUNATELY, I ONLY REALIZED THIS AFTER 20 YEARS

OF DOING IT. BUT I AM TELLING YOU THIS UPFRONT NOW. LISTEN TO

THE PATIENTS. THEY ACTUALLY KNOW MORE THAN YOU REALIZE. AND

THEN ADVOCACY. WE WILL TALK ABOUT BOTH INDIVIDUAL AND SYSTEMS

ADVOCACY. IT IS A RELENTLESS FIGHT ON BEHALF OF THE INDIVIDUAL

AND HOW ALL OF OUR SERVICES CAN INFORM THE SYSTEMS WORK WE DO.

AND SUPPORT WITH TRANSITION AND COMMUNITY INTEGRATION.

WE ARE GOING TO EXPLORE EACH OF THESE IN MORE DETAIL

ACROSS THE NEXT COUPLE OF DAYS. ANY QUESTIONS ABOUT THE

PHILOSOPHY AND HISTORY? ANY DISAGREEMENTS WITH ME ON ANYTHING

THAT WE HAVE SAID HERE?

AUDIENCE: I WOULD JUST LIKE TO INTRODUCE THE IDEA THAT

AMERICAN CULTURE, MAINSTREAM CULTURE, IT ENCOURAGES INDEPENDENCE AS

OPPOSED TO INTERDEPENDENCE. MAYBE CULTURES OTHER THAN AMERICAN

MAINSTREAM CULTURES PROMOTE INTERDEPENDENCE. SO, WHEN WE TALK ABOUT

INDEPENDENT LIVING IN SOME CASES, I THINK DEPENDING ON THE SUB

CULTURE THAT WE’RE WORKING WITH THAT SOMEBODY MIGHT BELONG TO,

WE MIGHT BE TALKING ABOUT INTERDEPENDENT LIVING.

BRUCE: THAT’S AN EXCELLENT POINT. I JUST GOT BACK FROM JAPAN.

I WAS VERY LUCKY IN REPRESENTING NCIL TO GO TO JAPAN. AND WHAT

WAS INTERESTING TO ME, WE TALKED A LOT ABOUT SOCIETAL NORMS.

IN JAPAN A SOCIETY RESPONSIBILITY TO TAKE CARE OF

SOCIETY AS A WHOLE AND WHAT I DESCRIBED AS THE SORT OF SOMEWHAT

HOSTILE PERIODIC PULL YOURSELF UP BY YOUR OWN BOOTSTRAPS KIND OF

U.S. MODEL. I TEND TO BE A LITTLE MORE -- OKAY. I HAVE A SERIES

OF DEFICITS THAT NO MATTER WHAT I DO, I CAN NEVER FIX. I CAN --

UNFORTUNATELY DRIVING. THEY SCATTER AROUND A NUMBER OF DIFFERENT

THINGS. I WILL NEVER RECOGNIZE PEOPLE THE WAY OTHER PEOPLE DO.

I WILL NEVER BE ABLE TO DRIVE FROM HERE TO THERE. ONE OF THE THINGS

THAT I LEARNED AND ONE OF THE THINGS THAT PEOPLE COLLECTIVELY

LEARN IS THIS LEVEL OF INDEPENDENCE. SO, THE MAINSTREAM CULTURE

TELLS US WE HAVE TO DO IT OURSELVES. WE KNOW NONE OF US CAN DO IT

ALL BY OURSELVES AND WE DO DEPEND ON EACH OTHER. I THINK THAT'S

ONE OF THE THINGS WHEN WE’RE LOOKING AT THE BROADER CONVERSATION ABOUT

DIVERSITY, WHAT THE DISABILITY COMMUNITY CAN BRING TO A BROADER

AMERICAN CULTURE IS THAT WE ARE INTERDEPENDENT. THAT'S A GREAT

POINT.

AUDIENCE: I DO WANT TO CAUTION US THOUGH AS A COMMUNITY

THOUGH IN THE INDEPENDENT LIVING MOVEMENT TO MAKE SURE THAT

WE -- THAT THE INDEPENDENT LIVING MOVEMENT UNDERSCORES WHAT YOU

JUST SAID. WHICH IS THAT THE INDEPENDENT LIVING MOVEMENT IS ABOUT PEOPLE

ACROSS THE BOARD WHO ARE GETTING SUPPORT ALL THE TIME. AND THAT WE

ARE DEPENDENT UPON EACH OTHER. AND THAT WE CAN CHALLENGE

NONDISABLED PEOPLE ABOUT DID YOU SOIL YOUR OWN PANTS THAT YOU

JUST PUT ON THIS MORNING? DID YOU FILTRATE THAT WATER

THAT YOU JUST OPENED THE FAUCET TO DRINK YOUR WATER? THERE IS

NO ONE AT ALL IN THIS ENTIRE PLANET THAT IS ABLE TO PULL

THEMSELVES UP BY THEIR OWN BOOTSTRAPS. THEY NEED TO BUILD

THEIR BOOTSTRAPS. I WOULD CAUTION US NOT TO IDENTIFY SUB

CULTURES. THERE IS A THING ABOUT – AND I’M GLAD WE ARE GOING TO TALK

ABOUT DIVERSITY. BECAUSE PEOPLE OF COLOR, AND I IDENTIFY AS SOMEONE

OF COLOR, THAT WE ARE NOT A SUB. AND WE HAVE BEEN PART OF

THE INDEPENDENT LIVING MOVEMENT ALL ALONG ALL THIS TIME. AND

THAT SO SERVICE DELIVERY IS REALLY IMPORTANT FOR ALL OF US IN

THIS ROOM TO NOT COMMUNICATE TO PEOPLE THAT WELL, I UNDERSTAND

THIS IS PART OF YOUR CULTURE TO, YOU KNOW, BLAH BLAH BLAH,

BECAUSE I THINK IT ALSO MAKES PEOPLE OF COLOR LIKE MYSELF FEEL

SEPARATED OUT FROM THE INDEPENDENT LIVING MOVEMENT. BUT I WOULD

TRUST THAT YOU ALL ARE GOING TO TALK ABOUT THAT. I JUST WANTED

TO, YOU KNOW, UP LIFT THAT THAT, YOU KNOW, WE ARE EQUAL IN OUR

COMMUNITY.

KIMBERLY TISSOT: I AM EXCITED TO TALK TO YOU. THIS IS ONE OF

MY FAVORITE TOPICS, WHY CILS ARE SO UNIQUE. WHEN YOUR CIL STANDS OUT,

I THINK THAT IS THE POWER. PEOPLE BEGIN ASKING FOR US TO BE AT THE

TABLE. PEOPLE ARE MISSING OUR PERSPECTIVE WHEN WE ARE NOT THERE.

SO SOME OF THE -- ONE OF THE FIRST REASONS WHY WE ARE UNIQUE IS WE

ARE CREATED. WE WERE CREATED. WE BEGAN WITH PEOPLE WITH

DISABILITIES FOR PEOPLE WITH DISABILITIES. SO VERY FEW

ORGANIZATIONS ARE SET UP LIKE THIS. AND THIS IS WHAT I PUT INTO

EVERY SINGLE ONE OF OUR GRANT APPLICATIONS IS SHOWING

HOW DIFFERENT WE ARE TO VR TO THE OTHER DISABILITY TYPE OF

ORGANIZATIONS.

WE ARE RUN AND OPERATED BY THE MAJORITY OF PEOPLE WITH DISABILITIES.

THIS IS A MANDATE. THIS IS NOT OPTIONAL. WHEN YOU ARE AT A

TABLE A BUSINESS TABLE, HOW MANY PEOPLE HAVE ORGANIZATIONS LIKE

THAT? YOU ARE OFTEN THE ONLY ONE AND THAT'S YOUR POWER. WE ARE

GROUNDED IN THE INDEPENDENT LIVING RIGHTS MOVEMENT. AND THAT IS

OBVIOUSLY GOING TO BE DIFFERENT AS WELL.

WE EMPOWER PEOPLE WITH DISABILITIES TO BE INDEPENDENT, TO

MAKE CHOICES. TO TAKE THE LEAD IN THEIR LIVES. A LOT OF THE

OTHER ORGANIZATIONS DO NOT. THEY CREATE DEPENDENCY IN THE WRONG

WAY.

WE PROMOTE DISABILITY RIGHTS AND DISABILITY PRIDE. WE ARE

PROUD OF WHO WE ARE WITH A DISABILITY AND WE KNOW HOW IMPORTANT

DISABILITY RIGHTS ARE TO ALLOW US TO HAVE EQUAL LIVES. AND THEN

WE ADVOCATE FROM THE PERSPECTIVE OF PEOPLE WITH DISABILITIES.

WHEN WE ARE AT THE TABLES, IT IS SO IMPORTANT THAT WE ARE ALWAYS

USING THAT PERSPECTIVE OF PEOPLE WITH DISABILITIES. THAT IS

OFTEN WHAT WE PREACH ABOUT AND I SOUND LIKE A BROKEN RECORD

EVERY TIME I AM AT A MEETING THAT PEOPLE WITH DISABILITIES ARE

NOT AT. WE ARE TALKING ABOUT SERVICES FOR PEOPLE WITH

DISABILITIES. HAVE YOU THOUGHT ABOUT INCLUDING A YOUTH WITH A

DISABILITY IN THIS CONVERSATION. HAVE

YOU TALKED ABOUT TARGETING THE POPULATION THAT YOU ARE CREATING

THE PROGRAM ABOUT. WE NEED TO BE INVOLVED IN THIS AND NEED TO

REMIND THE COMMUNITY THAT THEY HAVE TO START LISTENING TO US.

EVEN WITH SOME OF OUR LEGISLATIVE WORK THAT WE DO, WE HAVE

LEGISLATORS THAT CALL US CONSTANTLY AND ASK US ABOUT BILLS THAT

THE WORD DISABILITY IS MENTIONED. SO, THEY ARE ASKING OUR

OPINION. THAT'S THE KIND OF RELATIONSHIPS THAT WE MUST

ESTABLISH.

WE ARE A SAFE PLACE FOR PEOPLE WITH DISABILITIES. AND WE

SHOULD BE JUDGMENT FREE. WE SHOULD BE UNDERSTANDING. WE SHOULD

CHEER THEM ALONG, BUT MOST IMPORTANTLY, OUR ORGANIZATION SHOULD BE

SOMEWHERE THAT THEY FEEL COMFORTABLE WITH. THEY BRING SOME

FEARS. THEY BRING SCARY SITUATIONS THAT MAY BE OCCURRING AND

THAT WE ARE GOING TO SUPPORT THEM THROUGH THIS PROCESS.

A LOT OF CONVERSATION IN OUR ORGANIZATION LATELY HAS BEEN

AROUND MANDATED REPORTING. AND I DO NOT AGREE WITH -- I DO NOT

THINK CILS SHOULD BE MANDATED REPORTERS WITHOUT INCLUDING THE

PERSON WITH A DISABILITY IN THAT WHOLE PROCESS. WE CAN HELP

THEM ESCAPE ABUSE AND NEGLECT, BUT WE HAVE TO BE THEIR ALLIES IN

THIS. TURNING OUR BACK AND REPORTING THE SITUATION OFTEN STRIPS

THEIR RIGHTS AWAY.

ALSO, WE ARE FUNDED. WE HAVE TO REMIND PEOPLE ABOUT THIS.

WE ARE FUNDED UNDER TITLE VII OF THE REHABILITATION ACT.

CONGRESS RECOGNIZED THE IMPORTANCE OF CENTERS BEING DEVELOPED.

AND I HEAR VR SAYING, OH, WE ARE FUNDED BY THE REHAB ACT.

WELL, SO ARE WE AND SO WE ARE IMPORTANT.

AND WE ARE IMPORTANT PIECE AT THIS TABLE.

SO, WHAT IS NOT CONSIDERED CONSUMER DRIVEN? AND I HAVE SEEN

THIS THROUGHOUT THE U.S. AND SOME THINGS I JUST WANT TO REMIND

FOLKS THAT WE SHOULD REALLY, REALLY STAY AWAY FROM. AND SO, SOME

EXAMPLES. FIRST OF ALL, WHEN A CONSUMER DOESN'T DECIDE ON THE

DIRECTION OF THEIR SERVICES, THAT'S WHEN WE NEED TO STOP AND THINK WE

NEED TO SHIFT OUR POSITION ON THIS. SO, EXAMPLES THIS COULD BE

PARENTS, FAMILY MEMBERS, SERVICE PROVIDERS DECIDING ON GOALS AND

SERVICES. AND I THINK THERE HAS BEEN A LOT OF CONVERSATION

AROUND OUR YOUTH. PARENTS CAN BE INVOLVED, BUT YOU ALL ARE

PLAYING A VERY IMPORTANT ROLE WITH INTRODUCING TRANSITION AT ANY

AGE. YOU CAN INCLUDE A PARENT BUT LET THEM KNOW THE PHILOSOPHY

AND LET THEM KNOW THAT THEIR SON OR DAUGHTER IS GOING TO BE THE

ONE THAT WE ARE LOOKING TO AND THAT WE ARE WORKING DIRECTLY

WITH. AND SET THESE POLICIES AND PROCEDURES UP WITHIN YOUR

ORGANIZATION IN ADVANCE. WE TALK WITH SIX YEAR OLD'S, THREE YEAR

OLD'S SOMETIMES, AND JUST STARTING TO INCLUDE THEM. BECAUSE HOW

MANY OF YOU WISH YOU WERE INCLUDED IN THE EARLY CONVERSATIONS

ABOUT YOUR LIFE?

SERVICES THAT SEGREGATE OR REMOVE THE RIGHTS OF PEOPLE WITH DISABILITIES.

SO, GUARDIANSHIP. I HAVE SEEN CENTERS FOR INDEPENDENT LIVING

THAT HAD A FEE FOR GUARDIANSHIP. WHAT IN THE WORLD ARE WE DOING?

WE ARE ESSENTIALLY TAKING THE RIGHTS OF PEOPLE WITH DISABILITIES

AWAY BY HAVING SUCH PROGRAMS. WE NEED TO MOVE TO A DIFFERENT

POSITION LIKES SUPPORTIVE DECISION MAKING.

THERE ARE DAY PROGRAMS THAT ARE SHELTERED. PEOPLE

ARE SITTING IN A YUCKY ENVIRONMENT PLAYING BINGO ALL DAY OR

DOING THEIR NAILS. WE NEED TO STAY AWAY FROM THAT SHELTERED

WORKSHOP. WHERE PEOPLE ARE MAKING LESS THAN MINIMUM WAGE.

AND THEN SERVICES TO PARENTS AND FAMILY MEMBERS. I HAVE

SEEN A LOT OF CILS USE THIS WHERE THEY HAVE PEER SUPPORT GROUPS

FOR PARENTS. THAT IS NOT OUR POSITION. IF WE ARE GOING TO BE EDUCATING

PARENTS, WE NEED TO BE EDUCATING THEM IN THE PERSPECTIVE OF

PEOPLE WITH DISABILITIES. WE NEED TO TELL THEM HOW TO EMPOWER

THEIR CHILDREN. BUT SUPPORT GROUPS -- THAT IS FOR ANOTHER

ORGANIZATION TO DEAL WITH FOR PARENTS.

BRUCE: I THINK OTHER FAMILY MEMBERS THE OTHER END

OF THE AGE SPECTRUM YOU RUN INTO VERY SIMILAR DYNAMICS. SO THE

NUMBER OF TIMES I HAVE HEARD, WELL MOM CAN'T MAKE THESE DECISIONS

FOR HERSELF ANYMORE. THERE IS THIS SORT OF, YOU KNOW, WHEN WE

GET OLDER THERE IS THIS SENSE THAT OLDER ELDERLY PEOPLE NEED TO

HAVE THEIR DECISIONS MADE FOR THEM. AND I KNOW FIRSTHAND I RAN

INTO THIS WITH MY OWN MOTHER AS SHE WAS GETTING OLDER AND WITH

HER HEALTH ISSUES. MY SISTER DID WANT TO JUMP IN AND LIKE

MAKE DECISIONS FOR MOM OR SORT OF -- OKAY. THIS WOMAN WAS -- SHE

HAD CONTROL OVER EVERYTHING. SO, I LOOK LIKE A COMPLETE LAID

BACK PERSON COMPARED TO WHAT MY MOTHER WAS LIKE.

SO, THE THING WAS I WAS COMFORTABLE NOT HAVING CONTROL. IF

SHE WANTED TO MAKE EVERY DECISION WHATEVER IT WAS EVEN IF WHEN

WE GOT DOWN TO WHERE SHE NEEDED ME TO DRIVE HER SOMEPLACE. SHE

WOULD GIVE TURN BY TURN INSTRUCTIONS ON HOW SHE WANTED TO GO

EVEN THOUGH I HAD BEEN THERE A HUNDRED TIMES. I DIDN'T CARE.

IF YOU WANT TO DRIVE ME. BUT I THINK FOR ME, IT WAS MY GROUNDING

IN INDEPENDENT LIVING THAT REALLY HELPED ME DO THIS. BECAUSE

MAKE ALL OF THE DECISIONS. I AM JUST AN INSTRUMENT TO HELP MAKE

THAT HAPPEN FOR YOU. IT REALLY IS, YOU KNOW, IT CAN BE VERY

COMPLICATED.

KIMBERLY: EVEN WITH NEW DISABILITIES. PEOPLE COME IN

AFTER TRAUMATIC BRAIN INJURY OR THEIR FAMILY MEMBERS WILL COME IN.

YOU NEVER HAVE A CONSUMER WHO WALKS IN YOUR DOOR

AND SAYS HEY I WOULD LIKE GUARDIANSHIP PLEASE. THAT IS

NEVER GOING TO BE CONSUMER DRIVEN. TAKE MY RIGHTS AWAY, PLEASE.

NO, YOU ARE NOT GOING TO HEAR IT. SO, ANY QUESTIONS ABOUT WHAT

IS NOT CONSUMER DRIVEN SERVICES?

BRUCE: OR, OTHER EXAMPLES. CAN FOLKS THINK OF THINGS

THAT THEY HAVE RUN INTO THAT ARE EXAMPLES OF THINGS THAT ARE NOT

INDEPENDENT LIVING?

AUDIENCE: IT GOES BACK TO YOUR QUESTION. THAT WE DON'T

PROVIDE FAMILY SUPPORTS.

KIMBERLY: YES.

AUDIENCE: I UNDERSTAND IT NEEDS TO BE CONSUMER DRIVEN

BUT SOMETIMES IT CAN'T BE CONSUMER DRIVEN, UNLESS THE FAMILIES ARE

SEPARATED AND TAUGHT THAT IT IS OKAY FOR THE CHILD TO MAKE CHOICES

AND DECISIONS TOWARDS INDEPENDENCE. THE FAMILY SUPPORT

PIECE IS VERY IMPORTANT TO OUR CIL SO THEY ARE ABLE TO LET THEIR

CHILD BE ABLE TO HAVE THE FREEDOM TO MAKE CHOICES AND KNOW THAT

THEY ARE GOING TO BE SAFE IN MAKING THOSE CHOICES. IT IS LIKE A

CHANGE OF ATTITUDE AND I GUESS SOMEONE HAD SAID THE WORD SPECIAL

TO TAKE THE WORD OUT FROM A FAMILY.

IT IS TEACHING THE PARENTS THAT THEY CAN DO THIS THROUGH

SUPPORT AND THAT THEY ARE SAFE TO MAKE DECISIONS ON THEIR OWN.

SO, I AM A LITTLE BIT PERPLEXED BECAUSE THAT'S A BIG PIECE

OF WHERE WE ARE HEADED AS A CIL.

KIMBERLY: BE VERY CAREFUL WITH THAT BECAUSE YOU SHOULD

NOT BE USING ANY PART C FUNDING TO BE PROVIDING THAT KIND OF SERVICE.

AUDIENCE: AND WE ARE NOT.

KIMBERLY: BUT YOU ARE KIND OF SHIFTING AWAY IF THAT'S GOING TO

BE YOUR FOCUS. YOU CAN INTEGRATE. OBVIOUSLY WHEN WE ARE

WORKING WITH YOUNGER YOUTH, WE ARE WORKING ALONGSIDE WITH THEIR

PARENTS BUT MAKING SURE THAT THAT INDIVIDUAL IS THE KEY PART OF

THE SERVICE THAT WE ARE PROVIDING. YOU CAN MODEL YOU CAN

TEACH -- WE DO HAVE A TRANSITION CONFERENCE THAT WILL TALK ABOUT

IN A LITTLE BIT TODAY THAT WE HAVE A SECTION FOR PARENTS. BUT

THE WHOLE TIME WE HAVE OUR STAFF MEMBERS WITH DISABILITIES

TEACHING THEM ABOUT THE INDEPENDENT LIVING MOVEMENT AND ABOUT

EMPOWERING AND LETTING GO. BECAUSE TRANSITION IS NOT GOING TO EVER OCCUR

IF THEIR SKILLS AREN'T BEING TAUGHT. SO, WE HAVE TO EMPOWER BOTH THE

STUDENT, WHICH SHOULD BE OUR FOCUS, BUT ALSO WORKING WITH THE FAMILY RUN

ORGANIZATION. AND I KNOW THOSE ARE SOMETIMES THOSE ARE A LITTLE

MORE DIFFICULT TO WORK WITH. I THINK MAKING CREATING ALLIES

BECAUSE THAT IS WHAT THEIR POSITION AND FUNDING IS SUPPOSED TO

PROVIDE IS THAT FAMILY SUPPORT. AND WHAT WE HAVE DONE IS

PARTNERED WITH OUR PARENT TRAINING AND INFORMATION CENTER IN

SOUTH CAROLINA. SO, WE HAVE EMPOWERED THEM TO KNOW ABOUT THE

INDEPENDENT LIVING PHILOSOPHY AND HAVE EMPOWERED THEM. SO, WE

LEAVE SOME OF THAT TO THAT SPECIFIC ORGANIZATION. SO, WE DON'T

FOCUS. WE FOCUS ON THE INDIVIDUAL.

AND I CAN TALK MORE WITH YOU ABOUT THAT.

BRUCE: I THINK THAT WHOLE SEPARATION -- SO THAT

WHOLE ISSUE OF CHILDREN AND PARENTS AND SORT OF THAT NATURAL

SEPARATION THAT IS A HARD ONE. I THINK ONE OF THE THINGS THAT

WE ARE DOING THAT'S BEEN REALLY INTERESTING IS WE SUPPORT THE

LOCAL WHEELCHAIR TRACK AND FIELD TEAM.

AND THE WOMAN WHO HAS LED THAT WAS A PARA OLYMPIAN HERSELF

WHO WAS ALSO A MOTHER AND A GRANDMOTHER. SO, LISTENING TO

HER TALK, SHE HAD BEEN THROUGH THE EXPERIENCE ON BOTH SIDES.

SHE COULD ACTUALLY TALK TO PARENTS AND SAY BECAUSE SHE SAID THEY

ARE COMING IN. THESE ARE THEIR BABIES THAT THEY HAVE NEVER BEEN

ABLE TO LET GO OF AND THEY DON'T WANT TO LEAVE THE GYM AND THERE

IS NOTHING THAT IMPEDES A CHILD'S ABILITY TO EXCEL IN TRACK AND

FIELD THAN HAVING THEIR MOTHER WATCHING THEM RIGHT THERE. SO

SHE SAID, I WILL MAKE THEM GO OUT OF THE GYM. AND SHE SAID AND

THEN SHE SAYS, I WATCH THEM LOOK THROUGH THE WINDOW AT THE DOOR.

AND THEN SHE BASICALLY -- THEN THE NEXT WEEK SHE SAYS, OKAY YOU

CAN'T DO THAT ANYMORE. BUT BASICALLY, I THINK ONE OF THE THINGS

THAT IS GOOD ABOUT THAT EXPERIENCE FOR OUR FOLKS IS IT IS A

SETTING THAT IS NOT -- SO IT IS REALLY A CONTAINED SETTING. IT

IS NOT BIG LIFE DECISIONS. IT IS A NATURAL EXPERIENCE. KIDS

GOING OFF AND PARTICIPATING IN THESE ACTIVITIES AND THE PERSON

WHO IS SETTING THE LIMITS AND HELPING THEM THROUGH THE PROCESS

HAS BEEN SOMEONE WHO HAS DONE IT HERSELF AND KNOWS WHAT IT IS

LIKE TO BASICALLY BE DISMISSED AS SOMEONE -- WHEN SHE WAS A

CHILD.

KIMBERLY: ANY PARENT, RIGHT. AND SOMETHING THAT WE

ALSO DO AND WE WILL TALK ABOUT IS WE HAVE A YOUTH LEADERSHIP

GROUP THAT WE DO. AND THEY ACTUALLY TEACH A LOT OF THE FAMILY

MEMBERS THEMSELVES THROUGH THE OUTREACH THAT THEY DO. SO, IT IS

WAY BETTER TO HEAR IT FROM -- WE DEFINITELY DON'T WANT TO MEET

FAMILY TO FAMILY. WE WANT TO HAVE IT ALWAYS BE THE PERSPECTIVE OF THE

INDIVIDUAL WITH THE DISABILITY.

AUDIENCE: ANOTHER EXAMPLE WE

RUN INTO A LOT OF TIMES WHEN WE ARE WORKING WITH OTHER SERVICE

PROVIDERS AND THEY WILL REACH OUT TO US AND SAY WE HAVE A

REFERRAL FOR SOMEONE THAT WOULD LIKE TO WORK WITH YOU. AND

THERE IS AN EXPECTATION -- LIKE IF IT IS A CASEWORKER OR A SOCIAL

WORKER, YOU KNOW -- THERE IS AN EXPECTATION THAT THEY WANT THAT

WORK -- OUR WORKING RELATIONSHIP WITH THE CONSUMER -- TO KIND OF LOOK

LIKE WHAT THEIR WORKING RELATIONSHIP LOOKS LIKE. AND IT GIVES US

AN OPPORTUNITY TO KIND OF STEP IN AND REALLY EDUCATE OTHER

ORGANIZATIONS ABOUT THE IL PHILOSOPHY.

KIMBERLY: THAT'S A GREAT EXAMPLE, YES.

I LOVE THESE DISCUSSIONS.

AUDIENCE. WE HAVE A

RAMP PROGRAM AND BECAUSE IT IS A LOAN PROGRAM, WE DO REQUIRE THAT

THE APPLICANT -- AND WE WANT THE APPLICANT TO BE THE PERSON WITH

THE DISABILITY -- TO HAVE LEGAL POSSESSION AND CONTROL OF THE

PREMISES SO THAT WE HAVE THE RIGHT TO PUT A RAMP THERE. BUT IN

THE CASE OF SOMEONE WHO IS CONSERVED, THE CONSERVATOR HAS THE

LEGAL AUTHORITY. AND I AM UNCOMFORTABLE THAT WE ARE HAVING TO

WORK WITH THE CONSERVATOR IN ORDER TO GET THIS RAMP IN PLACE TO

HELP THE PERSON WHO HAS EXTREME ALZHEIMER'S. AND WE REALLY CAN'T

GET IT FROM HER.

SO, THIS FEELS VERY UNCOMFORTABLE TO ME BUT HOW DO WE HANDLE

CONSERVATORSHIP SITUATIONS?

KIMBERLY: AND THAT'S TOUGH. I MEAN THAT'S A REALLY

TOUGH SITUATION TO BE IN. AND I DON'T KNOW ABOUT YOUR LAWS IN

CALIFORNIA. THAT'S SOMETHING THAT YOU WOULD DEFINITELY WANT TO

EXPLORE TO LOOK AT ARE THERE ANY OTHER ALTERNATIVES TO THAT?

YOU KNOW. AND IS THE CONSUMER -- MEETING WITH THAT CONSUMER

INDIVIDUALLY TO SEE IF THEY CAN AT LEAST -- DO THEY WANT THE RAMP?

DO THEY CONSENT TO IT? HAVING THEM SIGN IT. AND THAT'S STILL -- I

MEAN DO THEY HAVE FULL GUARDIANSHIP?

AUDIENCE: IT IS CONSERVATORSHIP.

AUDIENCE: I ACTUALLY HAVE A LITTLE BIT DIFFERENT PERSPECTIVE.

I ACTUALLY WORKED IN IL FOR TEN YEARS A LONG TIME AGO.

TOOK A 15 YEAR BREAK AND WORKED FOR MEDICAID AND NOW I AM BACK

IN IL AGAIN. AND I THINK THE ISSUE IS THAT

WHEN I WORKED IN IL PREVIOUSLY, IT WAS ALL ABOUT THE CONSUMER.

EVERYTHING THE CONSUMER WANTS, THAT'S WHAT WE DO. FAMILY GO AWAY

GO AWAY. WE ARE NOT LISTENING BLAH BLAH BLAH BLAH BLAH BLAH.

BUT NOW THAT WE ARE ACTUALLY COMPELLED TO DO TRANSITION SERVICES, WE NEED

TO BE THINKING ABOUT FAMILIES AND WE NEED TO BE FIGURING OUT A

WAY. BECAUSE IF TODAY WE ARE NOT GOING TO DO SERVICES, WE ARE

ENDING UP SHOOTING OURSELVES IN THE FOOT. BECAUSE THESE YOUNG ADULTS ARE

WITH THEIR FAMILIES 24 SEVEN. SO WHATEVER GOOD WORK WE ARE DOING WITH

THEM WHEN WE ARE WITH THIS CHILD, IF WE ARE NOT ALSO

MAKING SURE THE FAMILY IS ACCEPTING WHAT WE ARE TEACHING

THEM, WE ARE NOT GETTING ANYWHERE. TO SAY WE ARE NOT GOING TO

PROVIDE SERVICES TO FAMILY MEMBERS, WE NEED TO BE MORE FLEXIBLE.

KIMBERLY: IT DOESN'T MEAN. AND THEY CAN BE INVOLVED,

BUT WHO IS IT WHO DECIDES THE GOALS?

AUDIENCE: I AM NOT GETTING INTO THE SEMANTICS TOO MUCH. I

UNDERSTAND THAT. I THINK IT IS STILL THE DIRECTION OF THE YOUNG

ADULT WHOEVER WE ARE TALKING ABOUT. WHOEVER THE CONSUMER IS.

THEY ARE IN CHARGE. BUT IF THE CONSUMER SAYS I WANT MY MOM AND

DAD TO BE PART OF THIS OR I WANT MY MOM AND DAD TO DO THIS. YOU

CAN'T SAY NO SORRY.

KIMBERLY: SOMETIMES IF IT IS THE CONSUMERS CHOICE -- IF

THEY WANT THEIR PARENT INVOLVED, THEY CAN BE INVOLVED. IT IS

STILL GOING BACK TO THEIR CHOICE. BUT IT IS ALSO MODELING FOR

THEM. BECAUSE IF THAT PARENT -- AND WE HAVE SEEN THIS A LOT WITH OUR

YOUTH GROUPS -- IF THE PARENTS ARE IN THERE, THERE IS NO

DISCUSSION. AS SOON AS THE PARENTS LEAVE, THEY HAVE A LOT TO

SAY. THAT'S WHERE WE NEED TO BUILD UP THEIR VOICE AND REALLY

BUILD UP THAT SELF-ADVOCACY. A LOT OF YOUTH HAVE ACTUALLY TAUGHT

THEIR FAMILIES TO LET GO BY THE WORK WE HAVE DONE WITH THEM.

AUDIENCE: I TOTALLY AGREE. IT JUST SEEMED VERY BLACK AND WHITE

THE WAY IT IS PRESENTED. AND I THINK IT NEEDS TO BE AN

UNDERSTANDING ABOUT THE WHOLE DYNAMIC AND ABOUT SETTING THE

STAGE FOR SUCCESS AND LASTING SUCCESS SO THAT THE CHILD IS

EMPOWERED TO THEN GO FORWARD AND TAKE CONTROL OF THEIR LIFE.

BUT AGAIN, THEY NEED TO HAVE FAMILY BE -- ALSO TO LET THEM.

SOMETIMES IN THE BEGINNING, THE FAMILY IS VERY RETICENT. THEY’RE

VERY RESISTANT. THAT'S WHERE AGAIN IT IS OUR ROLE AS THE

PROFESSIONALS IN THE ROOM, PEOPLE WHO HAVE GONE THROUGH A SIMILAR

PROCESS, TO EDUCATE THEM ABOUT YOU KNOW THIS HAPPENED TO ME.

THIS HAPPENED TO WHOEVER. AND GIVE THEM THE REASSURANCE

THAT THEY NEED TO BE ABLE TO GO FORWARD. THAT'S JUST MY POINT.

WE NEED TO MAKE SURE THAT ON A CASE-BY-CASE BASIS WE ARE NOT EXCLUDING.

KIMBERLY: THAT CAN BE DONE FOR ADVOCACY EVENTS AND

TRAINING EVENTS TOO. THAT COULD BE A WAY TO REACH PARENTS,

FOCUSING ON THAT YOUTH IS WHAT I THINK CENTERS FOR INDEPENDENT

LIVING SHOULD BE FOCUSED ON.

AMINA: I HAVE A COUPLE OF COMMENTS RELATED TO THAT

TOO. SO, ONE IS THAT IT OCCURRED TO ME AS WE ARE STARTING TO REACH

OUT TO YOUTH MORE, WORK WITH YOUTH MORE IS THAT BECAUSE WE

HAVEN'T INCLUDED FAMILIES OFTEN WE HAVEN'T BEEN AS WELCOMING TO

LATINO/CHICANO FAMILIES THAT LIKE TO DO THINGS TOGETHER OR NATIVE

AMERICAN FAMILIES THAT LIKE TO DO THINGS TOGETHER. AND SO, WE

NEED TO KIND OF BROADEN OUR PERSPECTIVE ABOUT THAT. AND SETTING

UP SITUATIONS. WE DID SOMETHING IN CONJUNCTION WITH THE PARENT

AND TRAINING CENTER WHERE THE PARENTS WERE ALL TOGETHER FOR SOME

PARTS AND THEN THE PARENTS WENT OFF FOR SOME PARTS AND THE

YOUTH WENT OFF FOR SOME PARTS. AND I THINK WE HAVE TO LOOK AT

THAT MORE. AND THE OTHER THING IS A SIMILAR SITUATION WITH AGING

PARENTS. THERE IS AREA AGENCY ON AGING. SOME OF THEM ARE MORE

PROGRESSIVE THAN OTHERS. BUT ONE THING OUR CENTER LEARNED IN

THAT WHOLE COLLABORATION THAT WE WERE SUPPOSED TO BE DOING, WAS

THAT MOSTLY THEY ARE USED TO WORKING WITH PEOPLE WHO HAVE BEEN

SO INDEPENDENT THAT BY THE TIME THEY ARE GETTING HELP, THEY NEED

TO BE TAKEN CARE OF. AND SO, THERE WAS A REAL CULTURE CLASH WITH

OUR CENTER AND OUR INDEPENDENT LIVING PHILOSOPHY AND OUR

PROMOTING INDEPENDENCE AND NOT PATERNALISM. AND THEREFORE, I THINK

WE HAVE A ROLE TO PLAY, ESPECIALLY WHEN WE ARE PROVIDING HOME

MODIFICATIONS AND PERSONAL CARE ASSISTANCE. THAT WE NEED TO KNOW

THAT WE ARE GOING TO BE WORKING WITH OLDER FAMILIES OR OLDER

PEOPLE WHO HAVE FAMILIES THAT ARE IN THE SAME KIND OF CARE

TAKING ROLE OR CONSERVATORSHIP ROLE AS THE ONES THAT WE ARE

SEEING WITH YOUTH. AND SO, AND THOSE FAMILIES DON'T HAVE

DISABILITY HISTORY. NOBODY HAS DISABILITY HISTORY OR

INDEPENDENT LIVING PHILOSOPHY EITHER. AND WE HAVE TO BE OPEN TO

SHARING THAT WITH THE AGING COMMUNITY AND THEIR YOUNGER

FAMILIES, AS MUCH AS WE ARE WITH THE PARENTS OF THE CHILDREN.

KIMBERLY: ABSOLUTELY. I THINK YOU ARE FOCUSING ON MY

SERVICES A LITTLE BIT NARROW. SO, I WANT TO TALK WITH YOU. WE

ARE GOING TO TALK WITH YOU ABOUT OUR YOUTH TRANSITION PROGRAM

THAT WE DO AS WELL THAT WE DO INVOLVE FAMILIES AND PARENTS. BUT

IT IS TOGETHER. WE ARE NOT PROVIDING THOSE INDIVIDUAL SERVICES

TO FAMILIES, BECAUSE WE ARE A DISABILITY RIGHTS ORGANIZATION. WE

PROMOTE INDEPENDENT LIVING AND AGAIN, THERE IS NO OTHER

ORGANIZATION LIKE OURS. SO, WE HAVE GOT TO EMBRACE THAT

DIFFERENCE.

AND WE HAVE A NUMBER OF YOUTH TRANSITION PROGRAMS THAT WE

DO. AND PARENTS ARE INVOLVED A NUMBER OF WAYS. EVEN COMING TO

OUR CENTER AND SEEING THE WAY THAT OUR STAFF WORKS. AND OUR STAFF

IS OFTENTIMES VERY EMPOWERING TO SEE. A LOT OF PARENTS HAVE

NEVER SEEN OR NEVER EXPECT FOR THEIR YOUNG ADULTS TO WORK

EVENTUALLY. AND SEEING SOMEBODY WITH A DISABILITY AT A CIL CAN BE

POWERFUL AND LIFE CHANGING TO THAT PARENT. THAT'S A POSITION

WE HAVE TO TAKE IT FROM.

NOW WE ARE GOING TO TALK ABOUT IL PRINCIPLES. SOMETHING A

LITTLE MORE LIGHTHEARTED. SO, THE INDEPENDENT LIVING MOVEMENT IS

FOUNDED IN THE BELIEF THAT PEOPLE WITH DISABILITIES REGARDLESS

OF THE FORM HAVE COMMON HISTORY. WE HAVE A SHARED STRUGGLE. WE ARE A

COMMUNITY AND CULTURE THAT WILL ADVANCE FURTHER BANDED TOGETHER

POLITICALLY. EQUAL OPPORTUNITIES AND RIGHTS ARE FOR ALL.

SO, THIS EXPLAINS US. VERY, VERY BRIEF.

BUT THERE SHOULD BE NO HIERARCHY IN THE CENTER

FOR INDEPENDENT LIVING EITHER. WE HAVE TO FOCUS ON THAT

CROSS DISABILITY. WE TRY VERY HARD NOT TO FOCUS ON A PARTICULAR

TYPE OF DISABILITY AND I KNOW THAT TAKES A LOT OF RESEARCH.

MAKING SURE THAT YOUR STAFF CAN ADJUST TO ANY KIND OF

CURRICULUM OR ANY KIND OF SERVICE TO MEET THE NEEDS OF ALL

PEOPLE WITH DIFFERENT TYPES OF DISABILITIES.

PEOPLE WITH DISABILITIES ARE THE BEST EXPERTS ON THEIR OWN

NEEDS AND THEY SHOULD DECIDE WHAT IS BEST FOR THEM. THAT'S AN

EASY CONCEPT. NO PERSON SHOULD LIVE IN AN INSTITUTION ON THE

BASIS OF DISABILITY.

HAVING A DISABILITY DOES NOT MEAN A PERSON IS SICK AND

REQUIRES A CERTIFIED MEDICAL PROFESSIONAL FOR DAILY LIVING. HOW

MANY OF YOU GET THESE CALLS? HEY, SO AND SO HAS AUTISM AND THEY

NEED SOMEBODY WITH THEM CONSTANTLY 24 HOURS A DAY. WE GET THOSE

CALLS. SO, WE ARE GOING TO TEACH YOU WHAT TO DO IN THOSE

SITUATIONS.

PEOPLE LEARN AND GROW FROM DISCUSSING THEIR NEEDS, CONCERNS

AND ISSUES WITH PEOPLE WHO HAVE HAD SIMILAR EXPERIENCES. THIS IS THE

MAGIC OF CILS. WE HAVE OFTEN TIMES BEEN IN THE SAME SITUATION AS

OUR CONSUMERS HAVE BEEN. WE CAN WALK THEM THROUGH IT, WE CAN

EMPOWER THEM THROUGH IT. THE WHOLE PROCESS. SYSTEMIC PROCESS

AND ADVOCACY EFFORTS ARE NEEDED TO MAKE SURE DISABILITY BENEFITS

FROM ALL THAT SOCIETY HAS TO OFFER. THIS IS SOMETHING WE HAVE

TO BE CAREFUL ABOUT. WHEN WE GO TO OUR SOUTH CAROLINA STATE

HOUSE, WE MAKE SURE THE VOICES OF ALL THE DISABILITY COMMUNITY IS

TOGETHER. WE MAKE SURE THAT WE HAVE A UNIFIED MESSAGE AND WE

REALLY TALK ABOUT THE BARRIERS THAT ARE IMPACTING ALL OF US AND

HOW WE CAN UNLOCK THOSE BARRIERS TOGETHER. SO, WE INVITE

DIFFERENT TYPES OF DISABILITY ORGANIZATIONS OUT TO ASSIST US

WITH THIS.

THERE SHOULD BE NO BARRIERS TO INDEPENDENCE INCLUDING

ARCHITECTURAL, COMMUNICATION, AND ATTITUDINAL BARRIERS. THIS IS WHAT

WE ARE FIGHTING TO REMOVE EVERYDAY. AND THEN THE ORGANIZATION

IS BEST SUITED TO SUPPORT AND ASSIST INDIVIDUALS WITH DISABILITIES

ARE GOVERNED AND OPERATED BY INDIVIDUALS WITH DISABILITIES AND

THAT IS US, YOU GUYS. SO, LEADERSHIP FOR INDEPENDENT LIVING AND

DISABILITY RIGHTS IS VESTED IN INDIVIDUALS WITH DISABILITIES AND

NOT PARENTS, SERVICE PROVIDERS, OR OTHER REPRESENTATIVES.

SOME IDEAS THAT CILS SHOULD LIVE BY. THIS IS ON OUR

WEBSITE AND SOMETHING WE LOOK AT OFTEN WHEN WE DECIDE ON ANY

SERVICES THAT ARE COMING IN TO OUR ORGANIZATION. THIS IS

SOMETHING THAT IF IT DOES NOT FIT WITHIN THESE CORE PRINCIPLES,

WE DO NOT MOVE FORWARD WITH THAT PROGRAM. SO, EMPOWERMENT. WE

DON'T REACH GOALS FOR INDIVIDUALS; WE TEACH THE SKILLS THAT

ALLOW THEM TO DO FOR THEMSELVES. AND THIS IS REALLY IMPORTANT.

WE DO NOT GO CATCH THE FISH FOR THEM, BUT TEACH THEM HOW TO FISH.

WE ARE SKILL BUILDING. INCLUSION. WE ADVOCATE FOR INDIVIDUALS

WITH DISABILITIES TO BE INCLUDED IN INTEGRATED ENVIRONMENTS IN THE

CLASSROOM, EMPLOYMENT, HOUSING, LEADERSHIP ROLES, AND IN DISCUSSIONS

THAT IMPACT THEIR LIVES AND THE DISABILITY COMMUNITY.

INDEPENDENCE. INDIVIDUALS WITH DISABILITIES HAVE THE RIGHT

TO CONTROL THEIR OWN LIVES AND MAKE DECISIONS ABOUT WHAT IS BEST

FOR THEM. WE BELIEVE EVERY INDIVIDUAL CAN BE INDEPENDENT. AND

THAT LOOKS DIFFERENT TO EVERYONE. THERE IS NO ONE SIZE FITS ALL

APPROACH. INDEPENDENCE COULD BE A CHOICE OF WHAT THEY ARE GOING

TO EAT OR WHAT THEY ARE GOING TO WATCH SOMETIMES. THAT IS A

VERY POWERFUL SKILL TO HAVE FOR YOURSELF TO MAKE THOSE

DECISIONS.

SO, EQUALITY. SO, WE TALK A LITTLE BIT ABOUT IT AND

SOMETHING I HAVE DONE WITH PARENTS OFTEN ESPECIALLY WHEN IT

COMES AROUND GUARDIANSHIP IS WE TALK A LOT OF FAMILIES OUT FROM

GETTING GUARDIANSHIP BECAUSE WE TALK ABOUT THE IMPORTANT PIECE OF

EQUALITY. WE TALK ABOUT DO YOU WANT YOUR SON OR DAUGHTER TO BE

SPECIAL? OR DO YOU WANT THEM TO BE EQUAL? AND 99% OF THE TIME

THE FAMILIES ARE SAYING THEY ACTUALLY WANT THEIR KID TO BE

EQUAL. THEY WANT THEM TO BE TREATED FAIRLY. AND SO, WE ADVOCATE

FOR EQUAL RIGHTS AND ACCESS AND NOT SPECIAL TREATMENT. WE DO

NOT WANT SEPARATE PROGRAMS. WE DON'T WANT TO BE TREATED

SPECIAL. WE WANT ACCESS. AND IN DISABILITY PRIDE. DISABILITY

IS NOT A NEGATIVE WORD. WE SHOULD BE USING DISABILITY. IT

MEANS THAT WE CAN BE MORE ADAPTABLE. WE ARE PROUD OF WHO WE ARE

AND THE BARRIERS WE HAVE OVERCOME AND THAT'S ONLY MADE US

STRONGER.

AND THEN SOME IMPORTANT TIPS. THIS IS SOMETHING THAT MADE

OUR ORGANIZATION VERY SUCCESSFUL IS THAT WE MAKE SURE THAT WE

ARE STAYING FOCUSED WITHIN THE IL PHILOSOPHY. WE DO NOT GO

OUTSIDE OF OUR FIVE CORE SERVICES AND WE’VE DIVERSIFIED

SIGNIFICANTLY OUTSIDE OF OUR FIVE CORE SERVICES -- WITHIN OUR FIVE CORE

SERVICES -- WITH OTHER FUNDING STREAMS. REALLY PAY ATTENTION.

STAYING FOCUSED ON THE IL PHILOSOPHY IS EXTREMELY IMPORTANT TO BEING

ABLE TO MOVE FORWARD, BUT ALSO TO CREATE THAT CHANGE IN THE COMMUNITY

THAT WE ARE ALL FIGHTING TO DO. DON'T CHASE FUNDING THAT

DOESN'T INCLUDE AND BENEFIT PEOPLE WITH DISABILITIES. I HAVE

SEEN CILS HAVE SOME OTHER PROGRAMS OUT THERE AND I AM LIKE HOW

IS THAT REALLY WORKING? AND HOW IS IT PROMOTING THE IL

PHILOSOPHY? ONLY COMMIT TO PROGRAMS AND PROJECTS THAT PROMOTE IL.

YES, MA'AM.

AUDIENCE: I WOULD LOVE TO HEAR EXAMPLES OF THE TYPES OF

PROGRAMS THAT YOU ARE THINKING LIKE WE DON'T REALLY THINK THAT'S

IN THE CORE SERVICES JUST TO HAVE CONTEXT.

KIMBERLY: OKAY. SO OF COURSE, WE HAVE SEEN

GUARDIANSHIP. WE HAVE SEEN WHERE CILS THAT ARE CHARGING PEOPLE TO

ASSIST WITH GETTING GUARDIANSHIP. THAT'S BEEN ONE OF THE MAIN

THINGS. HOW ARE THEY DOING THIS? ALSO, THERE HAS BEEN PROGRAMS

THAT I HAVE SEEN THAT ARE ACTUALLY SHELTER DAY PROGRAMMING THAT

HOW IS THAT PROMOTING IL? SO THOSE ARE SOME OF THE SCARIER

PROGRAMS THAT WE DO NOT WANT TO BE DOING...

BECOME THE BEST EXPERT ABOUT IL AND BECOME AN IMPORTANT

VOICE AT ALL OF THE TABLES, WE ARE REPRESENTING ALL PEOPLE WITH

DIFFERENT DISABILITIES AT THE TABLE. IF WE ARE USING THAT

MESSAGE, I PROMISE THE COMMUNITY IS HUNGRY FOR WHAT WE ARE

TRYING TO SAY AND WHAT WE ARE TRYING TO DO WITH OUR PHILOSOPHY.

AUDIENCE: CAN YOU GIVE SOME EXAMPLES OF HOW YOU DIVERSIFY WITHIN

THE CORE SERVICES? JUST FOR CONTEXT?

KIMBERLY: WE DO NOT WRITE ANY GRANTS THAT GO OUTSIDE

OF THE FIVE CORE SERVICES. WE HAVE 32 FUNDING STREAMS AT THE

MOMENT AND PART C IS ONLY A VERY SMALL PORTION OF WHAT OUR BUDGET IS NOW.

WHEN I CAME ON, WE WERE ACTUALLY 100 PERCENT PART C. I KNOW THAT SOME

CILS ARE STRUGGLING WITH THAT. AND LET ME TELL YOU, YOU CAN CHANGE.

IT TAKES A LOT OF HARD WORK, BUT YOU CAN DEFINITELY DIVERSIFY WITH

SOME CREATIVE THINKING. WE ARE GOING TO GO OVER OUR PROGRAMS THIS

AFTERNOON WITH WHAT OUR FUNDING LOOKS LIKE

ESPECIALLY WITH THE YOUTH TRANSITION PROGRAMS.

WE HAVE EMPLOYMENT PROGRAMS THAT ADDRESSES SYSTEM

ISSUES WITHIN OUR STATE AROUND EMPLOYMENT FOR PEOPLE WITH DISABILITIES.

WE WANT ALL EMPLOYERS TO BE ABLE TO HIRE PEOPLE WITH DISABILITIES

EVENTUALLY. SO, WE ARE DOING A LOT OF ADVOCACY WORK AROUND THAT.

WE HAVE SUPPORTED DECISION MAKING. A NUMBER OF OUR YOUTH PROGRAMS

ARE LED BY YOUTH WITH DISABILITIES FOR YOUTH WITH DISABILITIES, SO

THEY ARE EMBEDDED IN THE IL PHILOSOPHY. SO, IT IS A NUMBER.

AND WE WILL GO OVER THAT TODAY I PROMISE. AND THEN JUST REMEMBER

MISSION CREEPING DAMAGES OF THE IL PHILOSOPHY. SO, REALLY STAY

FOCUSED ON WHAT WE ARE DOING. I MEAN WE HAVE THE POWER TO REALLY

MAKE IMPROVEMENTS IN OUR COMMUNITIES AND PEOPLE -- I PROMISE

YOU PEOPLE ARE HUNGRY FOR WHAT WE ARE TRYING TO SAY.

BRUCE: AND ANOTHER EXAMPLE OF SORT OF A MISSION CREEP

THING AT LEAST OUR BOARD MADE THE DECISION. WE HAD RECEIVED A

LOT OF CAR SEATS. SO, FOR CHILDREN. SO, THERE WERE THE CAR SEATS

FOR KIDS WITH DISABILITIES MIXED IN WITH OTHER CAR SEATS. AND

THAT WAS SORT OF SOMETHING THAT THEY JUST KIND OF GIVE IT TO US.

WE DECIDED OKAY IT IS A GOOD THING. IT IS A NICE THING. BUT

PREVENTING DISABILITY AMONG CHILDREN IS NOT WHO WE ARE. SO, WE FOUND A

PARTNER THAT IT MADE MUCH MORE SENSE. SO, THE DISABILITY RELATED

STUFF WHERE WE COULD BE SUPPORTIVE OF KIDS WHO HAD SURGERIES AND

SUCH WHO NEEDED SPECIALIZED CAR SEATS, WE WOULD DEAL WITH THAT,

BUT THE REST OF IT WE ARE LIKE THAT’S NOT US.

KIMBERLY: BRUCE, I’M GLAD YOU BROUGHT THAT UP. PREVENTION SERVICES,

WHAT DOES IT LOOK LIKE WHEN AN ORGANIZATION RUN BY PEOPLE WITH

DISABILITIES ARE DOING PREVENTION? WHAT KIND OF MESSAGE IS

THAT SENDING?

BRUCE: THAT WAS THE EXACT CONVERSATION WE HAD AT

THE BOARD TABLE. IT REALLY IS INCUMBENT UPON THE DIRECTORS, THE

BOARD OF DIRECTORS TO REALLY THINK ABOUT THESE ISSUES AND TO

MAKE THESE KINDS OF DECISIONS AND TO THINK THEM THROUGH

THOROUGHLY. CREATING AN IL ENVIRONMENT WITH YOUR CENTER. ONE OF

MY FIRST SUPERVISORS SAID YOU HAVE A DEGREE IN ENGLISH. YOU

STUDIED THEATER. THINK ABOUT SPACE AS THEATER AND APPLY ALL OF

THAT EDUCATION TO THE WORLD. WHEN YOU COME INTO A CENTER, WHAT

DOES IT -- DOES THE ENVIRONMENT TELL YOU THAT YOU ARE SOMEPLACE

DIFFERENT THAN EVERY PLACE THEY HAVE EVER BEEN? OR FOLKS MAY

HAVE BEEN? WHEN YOU COME INTO OUR CENTER THERE ARE THREE BIG

PICTURES. IN THE RECEPTION AREA WITH BASICALLY COPS STANDING IN

FRONT OF POLICE CARS THAT ARE BLOCKING DOORS WITH DISABLED

PEOPLE BLOCKING THE CARS AND SOME WHO HAVE CLIMBED OUT OF THEIR

WHEELCHAIRS AND STUCK THEIR HEADS UNDER THE TIRES OF THE CARS.

WHEN YOU COME IN, YOU ARE NOT IN A UNITED CEREBRAL PALSY

ASSOCIATION AND YOU KNOW IT. AND ONLY ONCE WAS IT A LITTLE AWKWARD.

IT WAS WHEN WE HAD A BREAK IN AND THE POLICE OFFICER COMES IN

AND HE POINTS TO THE WALL AND SAYS I KNOW THIS OFFICER.

WHAT IS GOING ON IN THIS PHOTO. I SAID COULD WE FIND IF

THERE IS AN INTRUDER IN THE BUILDING FIRST AND THEN COME BACK.

I WILL GLADLY CHAT WHEN I DON'T FEEL IN DANGER. WE WANT TO

CREATE AN ENVIRONMENT WHERE FOLKS START FROM THE BEGINNING AND

REALIZE WE ARE A DIFFERENT PLACE. SO, ESTABLISHING A PHYSICAL

ORGANIZATIONAL ENVIRONMENT THAT REFLECTS OUR PHILOSOPHY AND THE

DIVERSITY OF OUR MOVEMENT. WE CAN DO THAT. A FULLY ACCESSIBLE

SPACE AND SERVICES.

SO, FOR US THAT MANIFESTED ITSELF IN WE HAVE LIKE EIGHT FOOT

WIDE HALLWAYS IN OUR OFFICE BECAUSE HONESTLY THE TINY FOUR FOOT

HALLWAY WE HAD IN OUR OLD BUILDING JUST DID NOT CUT IT. AND

THERE ARE MULTIPLE ROUTES TO GET ALMOST ANYPLACE. SO EVEN IF A

GROUP OF PEOPLE CAN CLOG UP A SINGLE HALL YOU CAN GET SOMEPLACE

ELSE. BUT HAVING THAT SORT OF SPACE. SOMETIMES IT’S LITTLE THINGS.

IN OUR RECEPTION AREA KNOWING THAT FOLKS WAIT A LONG

TIME. WE HAVE THE RESTROOMS. NONGENDER SPECIFIC RESTROOMS THE

VARIOUS TYPES OF ADAPTIVE EQUIPMENT PEOPLE NEED FOR THE

RESTROOM, VENDING MACHINES, ACCESS TO COMPUTERS. SO, HAVING A

SPACE WHERE FOLKS CAN ACTUALLY BE COMFORTABLE AND ACCESSIBLE.

CELEBRATING OUR MOVEMENT AND PRIDE THROUGH ARTWORK. WHEN YOU

COME INTO OUR CENTER YOU SEE THOSE PHOTOS OF PEOPLE PROTESTING.

BUT YOU ALSO SEE ARTWORK THAT DISABLED INDIVIDUALS HAVE DONE AND

PROVIDED TO OUR CENTERS. SO, CELEBRATING WHO WE ARE AS A

COMMUNITY. CREATING WE ARE MORE THAN JUST -- WE ARE A SOCIAL

JUSTICE ORGANIZATION, BUT WE ARE MORE THAN THAT AS A COMMUNITY

AND CELEBRATING ALL OF THAT. DISPLAYING IMAGES OF DIVERSE DISABILITIES,

RACES, AND CULTURES SO THAT EVERYONE FEELS WELCOME AND SAFE. SO, IF

YOU COME IN -- IT IS REALLY IMPORTANT WHEN YOU ENGAGE THAT THERE

IS A CONNECTION THAT IS MADE. WHEN YOU COME INTO OUR CENTER, WE

HAVE THAT ONE SPACE AT THE FRONT. IT HAS A TON OF STUFF AND ALMOST

EVERYONE CAN FIND SOMETHING IN THAT SPACE THEY CONNECT TO. I

AM NOT TALKING ABOUT WE’RE LIKE APPLEBEE’S SO WE WANT TO MAKE YOU FEEL

WELCOME. I’M TALKING ABOUT FOR MULTIPLELY MARGINALIZED INDIVIDUALS,

IT BECOMES MUCH MORE BASIC. AS A GAY MAN, A QUEER

MAN, ONE OF THE THINGS I WOULD DO IN ASSESSING A PLACE IS IT SAFE FOR ME

TO SELF DISCLOSE WHAT IS GOING ON IN MY LIFE HERE OR IS THIS A PLACE

WHERE I AM GOING TO POTENTIALLY EXPERIENCE SOME OTHER FORM OF

BIAS. I CAN CONTROL A LOT OF THAT IN MY LIFE. I HAVE THE

PRIVILEGE TO CHOOSE TO GO PLACES OR NOT. BUT SOME FOLKS WHO

COME TO CENTERS DON'T HAVE THAT. SO, LETTING THEM KNOW WHEN THEY

COME IN UPFRONT THAT THIS IS YOU’RE WELCOME HERE, BUT YOU ARE ALSO

SAFE. YOU CAN SEE IMAGES OF YOURSELF IN THIS SPACE. YOU KNOW

THAT WE AT LEAST KNEW ENOUGH TO START THERE.

THERE IS STILL A LOT OF OTHER WORK THAT GOES INTO THAT SO

BEYOND THAT. SO, ENSURING STAFF HAVE DISABILITIES AND OTHER

CHARACTERISTICS THAT ARE REPRESENTATIVE OF THE COMMUNITY THEY

SERVE. SO, IT IS NOT SO MUCH THAT WHEN YOU COME TO OUR CENTER, WE

HAVE PEOPLE WHO WILL TRY TO UNDERSTAND YOU AS A HISPANIC WITH

A DISABILITY. WE HAVE HISPANIC AND LATINO STAFF IN THE BUILDING. WE

CONSTANTLY -- SO I AM PROUD OF THE FACT THAT THERE ARE THREE

LANGUAGES CONSTANTLY IN USE IN OUR OFFICE -- SPANISH, ENGLISH, SIGN.

AND THAT AT ANY GIVEN POINT WHEN YOU COME IN, THERE IS SOMEONE

WHO CAN CONNECT WITH YOU IN A LANGUAGE THAT YOU ARE ACTUALLY

COMFORTABLE WITH AND UNDERSTAND THE CULTURAL ISSUES. WE GOT TO

A POINT WHEN WE WERE COMFORTABLE WITH THIS WHEN I HAD FOUR

LATINOS WITH DISABILITIES IN MY OFFICE, WHO WERE FROM VARIOUS DIFFERENT

CULTURES, AND THEY WERE ARGUING OVER HOW TO TRANSLATE OUR LANGUAGE FOR

THE COMMUNITY. AND THEY WERE LIKE, YOU HAVE TO DECIDE. AND MY

RESPONSE WAS OH, DEAR GOD, NO, I AM THE LEAST QUALIFIED PERSON IN

THIS ROOM TO MAKE THIS DECISION. LADIES, YOU HAVE PLENTY OF

TIME. WE WILL GIVE YOU THE TIME TO SORT THIS OUT. WE NEED TO

FIGURE OUT AN ANSWER COLLECTIVELY FOR ALL OF US. AT THAT POINT

I KNEW WHEN WE WERE HAVING ARGUMENTS IN OUR OFFICE ABOUT HOW TO

ACCURATELY PORTRAY THE IL PHILOSOPHY TO A VARIETY OF GROUPS OF

FOLKS, WE WERE ACTUALLY ENGAGED IN A GOOD CONVERSATION THAT

MEANT THAT PEOPLE WOULD FEEL CONNECTED AND THAT'S A REAL IMPORTANT

PART OF WHO WE ARE. AND I THINK WE ALL NEED TO LOOK AT

OURSELVES TO SEE WHETHER WE ARE ACTUALLY DOING THESE THINGS.

EVEN WHEN YOU THINK YOU ARE ACTUALLY DOING THEM, REALITY CHECK.

THERE IS STILL MORE TO BE DONE. CREATING EVEN AN ENVIRONMENT: WE ARE

MORE THAN SERVICE DELIVERY CENTERS. IT CAN BE EASY TO FALL

INTO THE SERVICE DELIVERY ASPECT OF THIS. ONE OF THE THINGS

THAT I THINK THAT CENTERS DO THAT IS MOST VITAL IS WE ARE WE

PROVIDE COMMUNITY SPACE WITH RESOURCES THAT INSURES WE ARE A

COMMUNITY BUILDING CENTER. THAT WE PROMOTE THE INDEPENDENT LIVING

PHILOSOPHY AND THE DISABILITY RIGHTS MOVEMENT.

WE DO A LOT OF SORT OF SOCIAL PROGRAMMING AND FUN STUFF

MIXED IN WITH THE STANDARD SERVICE DELIVERY AND THE HARD EDGE

ADVOCACY STUFF. AND I ALWAYS THOUGHT THE FUN STUFF IS JUST FUN.

WE DO IT BECAUSE WE ENJOY IT. IT IS PART OF WHAT WE SHOULD BE

DOING. AND THEN A FRIEND OF MINE POINTED OUT, HE SAID YOU KNOW

REALLY HAVING THIS SPACE WHERE YOU SOCIALIZE AND BUILD COMMUNITY

IS WHAT UNDERPINS THE SYSTEM'S ADVOCACY THAT YOU ARE DOING. AND HE

PUT IT INTO A FRAMEWORK. HE SAID MUCH LIKE THE CHURCHES IN THE

AFRICAN AMERICAN COMMUNITY PROVIDED SUPPORT TO THE CIVIL RIGHTS

MOVEMENT. I WAS LIKE I NEVER THOUGHT ABOUT IT LIKE THAT. I WAS

JUST HAVING A GOOD TIME AND WE WERE EATING. IT REALLY DOES. IN

THINKING ABOUT IT, WE HAVE THROUGH OUR CENTER BECAUSE OF THE

THINGS WE ARE DOING, WE HAVE BUILT A STRONG SENSE OF

COMMUNITY. PEOPLE CONNECT WITH EACH OTHER AND SUPPORT EACH

OTHER AND THAT GIVES US THE STRENGTH TO DO SOME OF THE HARDER

WORK THAT WE HAVE TO DO. AND AGAIN, SOCIAL OPPORTUNITIES. WAS

THAT A HAND? I WILL FINISH THE SLIDE AND THEN YOU ARE

IN THE QUEUE. INCLUDING OPPORTUNITIES FOR EVERYONE -- INCLUDING PEOPLE

WITH SIGNIFICANT DISABILITIES – TO PARTICIPATE IN OUR SYSTEMS ADVOCACY

AND OPERATIONALIZE OUR PHILOSOPHY. I THINK ONE OF THE THINGS THAT I

STRUGGLE WITH SOMETIMES IS BECAUSE OF ABLEISM IN THE COMMUNITY

AT LARGE. FOLKS WITH THE MOST SIGNIFICANT DISABILITIES ARE SOMETIMES

DISENFRANCHISED IN OUR OWN MOVEMENT AND WE NEED TO RECOGNIZE AND

ADDRESS THAT.

AUDIENCE: WHAT I AM INTERESTED IN IS WHAT DO YOU ALL SUGGEST ABOUT HOW

OUR STAFF ADDRESS THE CREATION OF IL ENVIRONMENT WHEN THEY ARE IN THE

COMMUNITY? SO MANY OF THE STAFF IN THE INDEPENDENT LIVING

DEPARTMENT ARE DOING THIS WORK ONLY IN PEOPLE'S OWN HOMES OR IN

THE NURSING FACILITIES OR IN THE SCHOOLS. SO CURIOUS ABOUT WHAT

SOME IDEAS ARE.

BRUCE: I THINK THERE ARE A COUPLE OF PARTS. HIRING

PEOPLE WITH SIGNIFICANT DISABILITIES IS KEY TO THIS. AND I

THINK MY EXPERIENCE IN JAPAN WAS INTERESTING TO ME. SEEING THE

MOVEMENT THERE WAS DIFFERENT IN THAT PEOPLE WITH VERY

SIGNIFICANT DISABILITIES WERE LEAVING IT. SO, CENTER DIRECTORS

BY IN LARGE WERE PEOPLE WHO HAD BEEN IN INSTITUTIONS. THE

MOVEMENT WAS MUCH MORE VISCERAL THAT WAY. IF YOU DON'T HAVE A

VISIBLE DISABILITY, IDENTIFYING OPPORTUNITIES TO SELF DISCLOSE

THAT INFORMATION AND BE UPFRONT ABOUT IT. OKAY YOU ALL KNOW A LOT

ABOUT ME WHEN I PRESENT. I DO THE SAME THING IN THE GENERAL

WORLD AS WELL. BECAUSE I WANT PEOPLE TO RECOGNIZE THAT I AM

PART OF THE DISABILITY COMMUNITY. I AM A PERSON WITH A DISABILITY.

IT IS WHO I AM. ONE OF THE THINGS THAT I DO INITIALLY IS I HAVE THE

ADAPT FLAG AND DISABILITY INTEGRATION BUTTON ON MY KNAPSACK THAT

I CARRY AROUND. HAVING IMAGES AND THINGS CONNECTED TO US

THAT ILLUSTRATE OUR COMMUNITY AND PRIDE.

THOSE ARE THINGS WE CAN BE DOING. ONE OF THE THINGS WE

STRUGGLE WITH SOMETIMES FOLKS OUT OF THE COMMUNITY WHO DO THAT

WORK FEEL DISCONNECTED. SO WE MAKE IT A POINT TO ACTUALLY TRY TO

CREATE MECHANISMS TO GET INFORMATION OUT SO THEY FEEL CONNECTED

TO THE CENTERS. SO THAT WHEN THEY ARE WORKING WITH FOLKS, THEY CAN

SAY, HEY, THERE IS THIS POTLUCK DINNER OR THERE IS THIS SOCIAL

THING COMING UP. WHY DON'T YOU JOIN US FOR THAT. SO, USING THOSE

COMMUNITY ACTIVITIES AS A WAY TO PULL PEOPLE IN.

AUDIENCE: IN TERMS OF HIRING PRACTICES, THERE IS ALSO -- AS

A HIRING PERSON, I HAVE TO I KIND OF COME TO IT -- AND THIS IS MAYBE

COMPLETELY A GIANT MISTAKE ON MY PART. THAT I ALSO COMPENSATED.

WE HAVE TERRIBLE INFRASTRUCTURES. WE HAVE DISABLED PEOPLE THAT

ARE TRAPPED IN THEIR APARTMENTS. WHO CAN'T GET IN AND OUT, SO

I HAVE STAFF THAT ARE ABLE TO CLIMB STAIRS OR WHATEVER THE

ENVIRONMENT IS THAT EXCLUDES DISABLED PEOPLE. THEY ARE GOING OUT

AND COMPENSATING. THAT'S HOW I PERCEIVE IT. SO MAYBE THAT’S A MISTAKE

IN MY HIRING PRACTICE. AND SO, WHEN YOU TALK ABOUT --

BRUCE: I DON'T SEE THAT AS A MISTAKE.

KIMBERLY: NO, IT'S’ NOT A MISTAKE.

AUDIENCE: BUT IT DOESN'T FULFILL WHAT YOU SAID WERE YOUR TOP

TWO IDEAS ABOUT BRINGING THE IL ENVIRONMENT, WHICH IS HIRING

PEOPLE WITH SIGNIFICANT DISABILITIES. AND THEN SOMETIMES PEOPLE

DO HAVE DISABILITIES, NONAPPARENT DISABILITIES, BUT THEY

HAVEN'T -- AND WHEN THEY COME TO US THEY HAVEN'T COME TO

TERMS WITH IT YET. SO, I AM TAKING YEARS AS A TRAINER

OR ACTUALLY THIS WHOLE CENTER IS TAKING YEARS TO HELP

SOMEBODY TO MAKE THEM FEEL COMFORTABLE TO DISCLOSE. I AM JUST

WRESTLING WITH THIS INFORMATION YOU ARE GIVING ME. I WANTED TO

KNOW IF YOU CAN TAKE ME FURTHER.

KIMBERLY: I THINK IT IS IMPORTANT THAT CILS AREN'T 100%

OPERATED WITH PEOPLE WITH SIGNIFICANT DISABILITIES AS WELL.

I THINK HAVING PEOPLE WITH DISABILITIES ON STAFF AND PEOPLE

WITHOUT DISABILITIES IS REALLY IMPORTANT TOO, BECAUSE.

WE ARE CREATING ALLIES. WE DON'T WANT TO BE A SEGREGATED

COMMUNITY EITHER WITHIN OUR OWN ORGANIZATION. SO, WE HAVE GOT TO

BE CAREFUL WITH THAT. SOMETHING WE DO, ESPECIALLY WHEN WE GO OUT INTO THE

SCHOOLS, IS WE HAVE DIFFERENT STAFF THAT WILL GO OUT INTO THE

SCHOOLS, BUT WE ALSO HAVE TRAINED YOUNG ADULTS WITH SIGNIFICANT

DISABILITIES GOING WITH THEM AND SHARING THAT MESSAGE OF

UNDERSTANDING. WHEN OTHER STAFF MAY BE TEACHING ABOUT THE

PHILOSOPHY AND BEING INDEPENDENT AND EMPLOYMENT OR WHATEVER THEY

ARE FOCUSED ON AT THAT TIME, BUT BRINGING SOMEBODY ELSE AND

CONNECTING THEM TO THAT PEER IS REALLY IMPORTANT.

BRUCE: I THINK THE QUESTION OF SELF DISCLOSURE IS

COMPLICATED. SO, I GET THAT. I THINK SOME OF WHAT WE CAN DO IS

CENTERS THOUGH IS RECOGNIZE -- AND THIS IS A NICE LEAD IN TO THIS

SLIDE -- THAT ABLEISM IS PERVASIVE AND CREEPS INTO OUR CONSCIOUSNESS

IN MANY DIFFERENT WAYS. SO THAT WE CARRY THAT WITH

US. IT IS NOT SOMETHING -- I WANT TO NOT USE ABLEISM AS THIS

SORT OF WAY TO CALL PEOPLE OUT. THEY ARE BEING ABLEISTS, BUT

AS A RECOGNITION OF. IT’S LIKE THE AIR WE BREATHE. ABLEISM

ABOUT WHO WE ARE DIMINISHES ALL OF US. SO, WE CAN ADDRESS SOME

OF THIS THROUGH LEADERSHIP, THROUGH OTHER FOLKS WITHIN THE

CENTER BEING COMFORTABLE IN SELF DISCLOSING, THROUGH MODELING THAT

INTERNALLY. CREATING A SPACE THAT IS SAFE FOR THAT.

SO, PEOPLE RECOGNIZE THAT'S PART OF WHO WE ARE. SO, I GET IT.

I’M FACE BLIND. I STRUGGLED WITH WHETHER I SHARED THAT INFORMATION

BECAUSE AS A QUEER MAN, I RECOGNIZE I AM POTENTIALLY SUBJECT

TO VIOLENCE AND MY THOUGHT WAS

IF I DISCLOSE THIS, DOES THAT PUT ME AT FURTHER RISK OF PEOPLE

ATTACKING ME AND THEN UNDERCUTTING MY ABILITY TO GET JUSTICE. BUT

IN THE END I DECIDED OKAY YOU KNOW WHAT THERE IS THAT

POSSIBILITY OF THE GREATER GOOD IS ACHIEVED BY BEING OPEN ABOUT

THESE CONVERSATIONS, TO BE PROUD OF WHO I AM, AND TO GIVE PEOPLE

THAT SPACE. SO, I THINK THERE REALLY IS -- I THINK AROUND INVISIBLE

DISABILITIES, IT CAN BE HARD TO MAKE THOSE DISCLOSURES.

ALRIGHT. CREATING A SEAMLESS SERVICE DELIVERY SYSTEM. HAVE YOU

EVER EXPERIENCED THE SOCIAL SERVICE RUN AROUND? DO YOU KNOW WHAT I

AM TALKING ABOUT? YES. SOMEONE IN XYZ DEPARTMENT CAN HELP YOU WITH

THAT. IT WAS HIDEOUS WASN'T IT? YOU CALL AND SOMEONE IS GOING

TO CALL SOMEBODY. YOU ARE GOING TO GET SOMEONE. THERE IS GOING

TO BE A CALL BACK AND YOU NEVER GET A CALL BACK. THAT IS

INCREDIBLY FRUSTRATING. WE WILL TALK A LITTLE BIT ABOUT

SEAMLESSNESS AND HOW WE CAN MAKE OUR CENTERS. I GET THAT IT IS

COMPLICATED. HOW CAN YOU HELP SUPPORT SOMEONE MOVE SEAMLESSLY

THROUGH YOUR CENTER PARTICULARLY AS YOU GET BIGGER? ONE OF

THE THINGS FOR OUR CENTER IS WE ARE A SERIES OF ORGANIZATIONS THAT ARE

COLLECTIVELY TOGETHER. SO, I THINK I CAN BRING A SENSE TO THIS

CONVERSATION AND WE WILL DO THAT LATER TODAY. BUT WHEN SOMEONE

CONNECTS WITH US MAKING SURE THEY GET TO WHERE THEY NEED TO GO

AND EVEN IF YOU REFER THEM OUT, THAT THEY KNOW THEY ARE GOING TO BE

SUPPORTED. IF YOU DON'T WANT CONSUMERS TO HAVE THESE

FRUSTRATING EXPERIENCES, WE NEED TO MAKE THINGS AS EASY FOR THEM

AS POSSIBLE. WHETHER IT IS CONNECTING THEM UP. WHEN THE PERSON

WHO COMES IN -- WHEN YOU CONTACT US – I THINK I TALK ABOUT THAT LATER.

I DO TALK ABOUT THAT LATER, I’M SURE. SO, IT IS THE DIRECT

CONNECTION TO FOLKS AND MAKING SURE THAT IT DOESN'T -- THEY DON'T

FALL THROUGH A GAP IN THE SYSTEM.

CILS CAN DO A GREAT DEAL TO ADDRESS HOW SERVICES WE PROVIDE CAN

OPERATIONALIZE OUR PHILOSOPHY AND BE AS SEAMLESS AS POSSIBLE. STARTING

POINT, I THINK. WE HAVE A LIVE PERSON ANSWERING THE PHONE, AS

OPPOSED TO A DEAD PERSON OR AN AUTOMATED DEVICE. SO HONESTLY

LOTS OF PEOPLE QUESTION, YOU KNOW, SHE CALLS PEOPLE HONEY. SHE

CALLS EVERYBODY HONEY. SHE CALLS ME HONEY. SHE HAS BEEN WITH

US LIKE 15 YEARS. KNOWS EVERYONE AND IS A LIVE PERSON WHO CAN

MAKE SURE PEOPLE GET TO WHERE THEY NEED TO GO. HAVING PEOPLE

WHO ARE ASSIGNED TO TALK TO SOMEONE. IF YOU COME TO OUR CENTER

AND YOU DO NOT HAVE AN APPOINTMENT, THERE IS SOMEONE WHO WILL

MEET WITH YOU. IF YOU CALL UP AND YOU DON'T KNOW WHO YOU ARE

TALKING TO, THERE IS SOMEONE WHO WILL TALK TO YOU RIGHT THEN. WE

GET A LOT -- WE BASICALLY HAVE GONE TO SOCIAL SERVICES AND THOSE

TYPES OF AGENCIES WHERE YOU ARE TOLD PLEASE WAIT IN THE SECURE

LOBBY AND SOMEBODY WILL COME AND ASSIGN YOU A NAME TAG. THE

CENTER SHOULD NOT BE LIKE THIS. WE SHOULD BE A COMMUNITY AND

WE SHOULD BE WELCOMING. THESE ARE WISE WORDS. THESE ARE NOT

MINE, BUT I THINK IT MEANS A LOT. THEY MAY NOT REMEMBER WHAT

YOU SAID, AND THEY OFTEN DON'T, BUT THEY WILL REMEMBER HOW YOU

MADE THEM FEEL. SO, IN THE END WHEN WE ARE LOOKING AT HOW WE ARE

DELIVERING SERVICES, MAYBE IT ISN'T THAT WE DIDN'T HAVE THE

PERFECT ANSWER AND WE COULDN'T SOLVE THEIR PROBLEM, BUT THEY

EXPERIENCED EMPATHY. THEY KNEW THAT SOMEONE ELSE ACTUALLY CARED

ABOUT WHETHER THEIR NEEDS WERE MET. IN THE END, FOR A LOT OF THE

FOLKS WE CONNECT WITH, JUST KNOWING THAT THERE IS A PERSON OUT IN

THE WORLD, WHO ACTUALLY CARES ABOUT WHAT IS GOING ON IN

THEIR LIFE CAN ACTUALLY CHANGE THE COURSE OF EVENTS FOR THEM.

AND THAT'S REALLY, REALLY IMPORTANT. EVEN WHEN THE ANSWER IS, WE

DON'T HAVE A SOLUTION FOR THIS, YOU KNOW, AND IT IS GENERALLY

NEVER THE ANSWER. THERE IS ALWAYS SOME KIND OF SOLUTION, EVEN IF

IT IS SYSTEMS ADVOCACY. JOIN US, WE WILL CHANGE THAT LAW.

GIVING PEOPLE HOW THEY FEEL IS REALLY IMPORTANT. AND THEN WE

HAVE RESOURCES. QUESTIONS? COMMENTS? MICHELLE?

MICHELLE: IF WE COULD GO BACK, I WOULD LIKE FOR YOU TO

CLARIFY ABOUT THE FAMILY SERVICES AND THE PREVENTIVE

SERVICES. BECAUSE FOR THOSE OF US WHO WRITE THE 704, THOSE

SERVICES ARE ON THE 704. WHEN YOU SAY YOU DO NOT PROVIDE

PREVENTIVE SERVICES, FOR THOSE OF US WHO HAVE HEALTH AND FITNESS

PROGRAMS, THAT'S CONSIDERED PREVENTIVE SERVICE. I WOULD LIKE FOR

YOU GUYS TO KIND OF CLARIFY SO SOME OF US DON’T LEAVE HERE

SAYING YOU CAN'T DO THAT WITH PART C PROGRAMS. I DO KNOW THAT

IN SOME PART C PROGRAMS THAT ARE ALLOCATED FOR FUNDING IN THE STATE

THEY ASK US TO PROVIDE AT LEAST TWO MORE ADDITIONAL SERVICES.

SO, I WOULD LIKE FOR YOU GUYS TO CLARIFY THAT. BECAUSE I WOULD

HATE FOR SOME PEOPLE TO GO HOME AND THINK THEY CAN'T DO THAT.

BRUCE: I WANT TO BE CLEAR. I WAS NOT SAYING. I

WASN'T SAYING YOU CAN'T USE PART C FUNDING. YOU CAN'T USE IL

FUNDING TO PROVIDE SPECIFIC THINGS. WHAT I REALLY WANTED PEOPLE

TO DO WAS RECOGNIZE THAT WHAT – IT WAS SORT OF BUILDING UP A POINT. IT

IS A THOUGHTFUL PROCESS WHAT YOU DO IN TERMS OF MISSION CREEP. BECAUSE IT

IS VERY EASY. THERE IS A GRANT THERE. I WANT TO GO DO THAT. I

REALLY SORT OF GET -- IT RUBS ME THE WRONG WAY WHEN I SEE FOLKS

GOING OUT AND SAYING DON'T GO OUT AND DO THESE THINGS BECAUSE

YOU WILL BECOME BRAIN INJURED AND IT IS A HIDEOUS EXPERIENCE.

LOOK AT THESE PEOPLE. AS SOMEONE WHO IS NOT NEURO TYPICAL, IT

REALLY IS ANNOYING TO ME THAT I COULD BE HELD UP AS AN EXAMPLE

OF SOMEONE WHO YOU DON'T WANT TO BE LIKE. YOU DON'T WANT TO END

UP LIKE HIM. OBVIOUSLY, I KNOW I REPRESENT LIKE SOMEONE WITH A BRAIN

INJURY. MY DOCTOR ONCE ASKED ME, HE SAID, DID YOU HIT YOUR

HEAD? NOT QUITE, BUT WHY DO YOU ASK? HE SAID, IT TAKES ONE TO KNOW

ONE. THAT PEER SUPPORT PIECE AND DISABILITY PRIDE IS REALLY

ANTITHETICAL TO SOME OF THAT DON'T GO OUT AND BECOME LIKE US.

AND THAT’S WHAT I WAS REALLY TRYING TO SAY.

MICHELLE: AND I TOTALLY UNDERSTAND THAT AND I DO KNOW

THAT SOME BOARDS HAVE FUNDING PARAMETERS IN PLACE. THAT'S THE

REASON WHY I WANTED TO EXPLAIN. I UNDERSTAND WHERE YOU ARE

COMING FROM. I WANTED YOU TO EXPLAIN THAT FOR THOSE WHO ARE NEW

HERE AND THOSE WHO WILL BE WRITING THE 704 REPORTS.

BRUCE: I LIKE THE IDEA THAT WE MAKE THOUGHTFUL

DECISIONS ABOUT THESE THINGS AS OPPOSED TO JUST RANDOMLY CHASING

THE MONEY. I THINK ADDING MISSION CREEP IN THERE IS IMPORTANT.

KIMBERLY: YES, ABSOLUTELY, AND PREVENTATIVE IS JUST REALLY

PREVENTING DISABILITY. WE ARE PRIDEFUL OF WHO WE ARE.

AND SO, WE WANT TO MAKE SURE WE ARE SENDING A MESSAGE THAT YOUR

LIFE IS NOT OVER WHEN YOU HAVE A DISABILITY. JUST BEING MINDFUL OF

THE DIRECTION OF YOUR ORGANIZATION. FAMILY SERVICES. I

INTERPRET THAT OUR BOARD OF DIRECTORS INTERPRET THAT AS PEOPLE

WITH DISABILITIES CREATING FAMILIES. AND SO, OUR FOCUS HAS BEEN

A LOT ON PARENTS WITH DISABILITIES WITHIN OUR ORGANIZATION.

AND HOW PEOPLE WITH DISABILITIES

WORK WITHIN THE FAMILY DYNAMIC AND EDUCATING THEIR FAMILY

MEMBERS. THAT'S WHAT WE INTERPRET FAMILY SERVICES FOR.

MICHELLE: OK AND JUST TO CLARIFY ABOUT THE PREVENTIVE SERVICES.

PREVENTATIVE IS PRETTY MUCH PREVENTING ADDITIONAL...

KIMBERLY: RIGHT. LOOKING AT HEALTHY EATING COULD BE A

PREVENTATIVE FOR SECONDARY TYPES OF ILLNESSES. SO THAT COULD BE

SOMETHING THAT HOLDS IN THAT LINE. ANY OTHER QUESTIONS?

 (APPLAUSE).