IMPLEMENTING OR STRENGTHENING EFFECTIVE INDIVIDUAL AND SYSTEMS ADVOCACY ACTIVITIES

PRESENTERS: BRUCE DARLING AND KIMBERLY TISSOT

KIMBERLY TISSOT: I'M GOING TO START TALKING ABOUT

SOME REALLY FUN STUFF -- THE REHABILITATION ACT.

I'M GOING TO GO OVER SOME OF THE TITLES BECAUSE

THIS IS VERY IMPORTANT WHEN WE GO OUT AND

WE ADVOCATE AND WE START TALKING WITH LEGISLATURES,

WE WANT TO EXPLAIN HOW CENTERS GOT STARTED

AND WHAT WE ALL ARE ABOUT. SO, I'M GOING TO

START WITH JUST THE SIMPLE TITLES OF

THE REHABILITATION ACT.

TITLE 1 IS VOCATIONAL REHABILITATION SERVICES.

AND THAT STARTED THE STATE REHAB COUNCIL, VR SERVICES.

TITLE 2 IS RESEARCH AND TRAINING AND THAT IS

RESEARCH AND TRAINING AROUND DISABILITY,

INDEPENDENT LIVING, AND REHABILITATION.

TITLE 3 IS PROFESSIONAL DEVELOPMENT AND

SPECIAL PROJECTS AND THAT ALSO GIVES THE --

DECLARATION OF COMPETITIVE GRANTS, BUT ALSO

DIFFERENT TRAINING PROGRAMS FALL UNDER THAT.

TITLE 4 IS WHAT ESTABLISHED THE NATIONAL COUNCIL

ON DISABILITY AND THAT GIVES THE COUNCIL SOME

DUTIES AND AUTHORIZATIONS.

TITLE 5 IS RIGHTS AND ADVOCACY. SO, THIS IS

THE NONDISCRIMINATION PART FOR FEDERAL PROGRAMS.

TITLE 6 IS EMPLOYMENT OPPORTUNITIES FOR PEOPLE

WITH DISABILITIES AND THAT ESTABLISHES VRS

AND THE ELIGIBILITY, RESTRICTIONS AND SERVICES

AND THEN OUR FAVORITE, MOST IMPORTANT, RIGHT?

IT IS TITLE VII AND THAT'S INDEPENDENT LIVING

SERVICES AND CENTERS FOR INDEPENDENT LIVING.

SO THAT TALKS ABOUT THE ADMINISTRATION, CILS,

SILCS, TECHNICAL ASSISTANCE, STANDARDS AND ASSURANCES.

AND THEN ALSO WHAT IS REALLY IMPORTANT TO NOTICE

IS THAT TITLE VII IS THE ONLY ONE THAT MENTIONS

CONSUMER CONTROL AS PART OF FOUNDATION AND

PHILOSOPHY OF THE FUNDING. SO THAT IS WHAT

MAKES US STAND OUT FROM ALL THE OTHER TITLES

IN THE REHAB ACT.

SO, IN THE REGS YOU'LL ALSO SEE THAT

INDEPENDENT LIVING PHILOSOPHY IS FIRST

IN THE LAW AND WE TALKED A LOT ABOUT THIS

ALREADY, SO I'M GOING TO BRIEFLY GO OVER

SOME OF THIS BECAUSE YOU ALL KNOW A LOT OF THIS.

SO, CONSUMER CONTROL WE TALKED A LITTLE BIT

ABOUT THAT AND WE'RE GOING TO TALK MORE

ABOUT THAT IN THE NEXT SLIDE.

PEER SUPPORT. SO, THIS IS ALL OF WHAT THE

PHILOSOPHY AND THE REGS TALK ABOUT.

SELF-HELP AND SELF-DETERMINATION.

EQUAL ACCESS WITHIN OUR PROGRAMS AND

SERVICES THAT WE PROVIDE.

INDIVIDUAL AND SYSTEMS ADVOCACY AND

BRUCE AND I ARE GETTING READY TO EXPLAIN

MORE ABOUT THAT. AND THEN MAXIMIZING LEADERSHIP,

EMPOWERMENT, INDEPENDENCE AND PRODUCTIVITY OF

PEOPLE WITH DISABILITIES. AND THEN, PROMOTING

INTEGRATION AND FULL INCLUSION FOR PEOPLE

WITH DISABILITIES INTO THE MAINSTREAM (AND I

DON’T LIKE THAT WORD) OF AMERICAN

SOCIETY BY FUNDING OUR IL NETWORKS

AND OUR CENTERS FOR INDEPENDENT LIVING.

SO, WHAT IS CONSUMER CONTROL, AND WE TALKED

A LOT ABOUT THIS, BUT WE'RE GOING TO GO INTO A

LITTLE MORE DETAIL. IT'S OBVIOUSLY 50 PERCENT

OR MORE OF OUR BOARD MUST BE PEOPLE WITH SIGNIFICANT

DISABILITIES AND THAT IS SELF-REPORTING.

MORE THAN 50 PERCENT OF OUR MANAGEMENT ON OUR

CENTERS FOR INDEPENDENT LIVING MUST BE AND

I THINK THAT IS THE ONE PEOPLE DON'T OFTEN REALIZE.

WHEN I'M GOING OUT TO OTHER CILS, I SEE THAT

THAT IS OFTEN OVERLOOKED. 50 PERCENT OF STAFF

OF CENTERS MUST BE PEOPLE WITH DISABILITIES,

AS WELL, AND THIS IS SELF-REPORTING.

SOMETHING THAT WE DO FOR SELF-REPORTING IS

WE SEND OUT A SURVEY TO OUR STAFF ANNUALLY

AND WE COLLECT THIS INFORMATION. OBVIOUSLY,

WE ALSO KNOW THIS USUALLY AT HIRE, BECAUSE A

LOT OF PEOPLE LIKE TO DISCLOSE TO US,

WHICH IS GREAT. BUT WE SEND IT OUT,

JUST SO WE HAVE DOCUMENTATION. SO THAT

IF WE DO GET AN AUDIT, WE CAN ACTUALLY SHOW

DOCUMENTATION FOR OUR PROGRAM PERFORMANCE REPORT (PPR

THE SILC ALSO HAS TO BE MADE UP OF 50 PERCENT –

THE MEMBERS OF THE SILC MUST BE PEOPLE WITH

DISABILITIES WHO DO NOT WORK IN A CIL OR A STATE AGENCY.

SO, AN INDIVIDUAL WITH DISABILITY, IN OUR

DEFINITION, MEANS AN INDIVIDUAL WITH A SEVERE

PHYSICAL OR MENTAL IMPAIRMENT, AND I DO NOT LIKE

TO USE THAT WORD, THAT SUBSTANTIALLY LIMITS ONE

OR MORE MAJOR LIFE ACTIVITIES. AND THIS IS ALL

SELF-REPORTING. YOU DO NOT NEED DOCUMENTATION.

AND THIS IS SOMETHING THAT SETS US APART, AS WELL,

BECAUSE THERE IS NO ELIGIBILITY PROCESS.

HOW MANY OF YOU ARE REALLY -- WHEN A CONSUMER CALLS,

THEY'RE EXCITED TO BE ABLE TO TELL YOU THEY HAVE A

DISABILITY AND NOT HAVE TO SHOW YOU THE PAPERWORK

THEY HAVE TO GO THROUGH IN THE VR PROCESS. AND ALSO,

IN THE DEFINITION HAS A RECORD OF SUCH IMPAIRMENT; OR IS

REGARDED AS -- AND THIS IS THE DEFINITION WITHIN

THE AMERICANS WITH DISABILITIES ACT. AN INDIVIDUAL

WITH A SIGNIFICANT DISABILITY IS ALSO SELF-REPORTING.

IT JUST MEANS AN INDIVIDUAL WITH A SEVERE PHYSICAL OR MENTAL

IMPAIRMENT, AND I HATE THAT WORD AGAIN, WHOSE ABILITY

TO FUNCTION INDEPENDENTLY, IN THE FAMILY OR

COMMUNITY OR WHOSE ABILITY TO OBTAIN, MAINTAIN

OR ADVANCE IN EMPLOYMENT IS SUBSTANTIALLY LIMITED.

WHEN YOU ASK THIS QUESTION WITH YOUR CONSUMERS,

THEY REALLY DON'T KNOW WHAT YOU MEAN.

WHEN YOU SAY, DO YOU HAVE A SIGNIFICANT DISABILITY?

HOW MANY OF YOU WANT TO SHARE WHAT YOUR CIL DOES TO

COLLECT THIS INFORMATION? YES?

AUDIENCE: THIS IS ROBBIE FROM ATLANTIS. WHAT WE TRY

AND DO DURING THE INTAKE PROCESS IS JUST GO A

LITTLE BIT DEEPER INTO THAT CONVERSATION ABOUT,

YOU KNOW, A SIGNIFICANT DISABILITY.

WHAT WE DO IS EXPLAIN WHAT THAT MEANS.

IF IT IS IMPACTING OR LIMITING YOUR ACTIVITIES

FOR DAILY LIVING, THEN THAT IS SIGNIFICANT.

KIMBERLY: IS THAT ALSO ON YOUR ELIGIBILITY FORM?

AUDIENCE: YES.

KIMBERLY: AND SOMETIMES YOU HAVE TO EXPLORE

WITH PEOPLE WITH DIFFERENT DISABILITIES AS WELL,

BECAUSE SOMETIMES PEOPLE DON'T LIKE TO DISCLOSE

A PSYCHIATRIC DISABILITY, SO YOU LEARN ABOUT THEM

THROUGH THE PROCESS AND YOU CAN ALWAYS GO BACK

AND ADD SOME OF THE DISABILITIES IN THE CATEGORIES.

AS LONG AS THEY TELL YOU. NEVER ASSUME.

AND THE PHILOSOPHY OF EQUAL ACCESS, WHICH IS REALLY

I THINK WHAT MAKES CENTERS SO IMPORTANT IS THAT

THERE'S AN EXPECTATION THAT ALL OF OUR OPERATIONS

ARE GOING TO BE FULLY ACCESSIBLE. AND SO,

THIS MEANS FOR COMMUNICATION TO MAKING SURE YOU

HAVE YOUR INTERPRETERS THAT YOU WORK WITH.

YOU DON'T NECESSARILY HAVE TO HAVE INTERPRETERS

ON STAFF, BUT MAKING SURE YOU HAVE A COMPANY

THAT YOU CONTRACT WITH TO PROVIDE THESE

INTERPRETING SERVICES. YOU KNOW, DIFFERENT READERS.

IF YOU'RE HAVING A CONFERENCE AND PEOPLE ARE

REQUESTING A REASONABLE ACCOMMODATION, YOU

DEFINITELY WANT TO HAVE CAPTIONING. ANY VIDEOS

SHOULD BE FULLY ACCESSIBLE THAT YOU'RE PRODUCING.

SO, MAKING SURE THAT YOU'RE CREATING THEM IN

DIFFERENT FORMATS BUT ALSO BE VERY CAREFUL.

I KNOW THAT SOCIAL MEDIA IS PRETTY BIG.

YOU KNOW, MAKING SURE THAT PLATFORM. THAT

WHAT YOU'RE POSTING ON SOCIAL MEDIA IS FULLY

ACCESSIBLE, TOO. I SEE A LOT OF CILS THAT POST

PICTURES, BUT THEY'RE NOT PUTTING ANY CAPTION TO

THOSE PICTURES, SO PEOPLE WHO ARE BLIND ARE NOT

ABLE TO FULLY PARTICIPATE IN WHAT YOU'RE POSTING.

HAVING ALTERNATE FORMATS AVAILABLE UPON REQUEST

WITHIN YOUR ORGANIZATION, LARGE FONT.

I KNOW BRAILLE IS KIND OF GETTING OUT-DATED

 A LITTLE BIT. SO, YOU WOULD WANT TO MAKE

SURE THAT YOU'RE ABLE TO PROVIDE A FORMAT --

ELECTRONIC FORMAT TO A LOT OF PEOPLE WHO USE

COMPUTERS OR SMARTPHONES. AND THEN PHYSICAL

ACCESS TO ALL SITES USED WITHIN THE ORGANIZATION

AND WE TAKE THIS REALLY SERIOUSLY.

WE HAVE SEVERAL TYPES OF DIFFERENT EVENTS,

INCLUDING OUR ANNUAL FUNDRAISER. WE HAVE A

STATEWIDE CONFERENCE AND WE DO AN EMPLOYMENT

SUMMIT. BEFORE WE BOOK ANY VENUE, WE GO OUT AND WE

MAKE SURE THAT IT'S FULLY ACCESSIBLE

SO, WE LOOK AT THE BATHROOMS. AND IF WE'RE RESERVING

HOTEL ROOMS, WE GO AND ACTUALLY LOOK AT THE ROOMS

TO MAKE SURE THAT IF ANYBODY'S ARRIVING THAT

USES MAYBE A HOYER LIFT, THAT THERE'S ROOM UNDER

THE BED TO BE ABLE TO ACTUALLY USE THE HOYER LIFT.

SO, IT’S IMPORTANT. DON'T EVER BOOK A VENUE

WITHOUT SEEING IT. AND THEN, OF COURSE, OUR

OWN PHYSICAL CILS MUST BE FULLY ACCESSIBLE.

AND THEN SOMETHING THAT I FORGOT TO PUT ON

HERE, TOO, IS HOW YOU'RE GOING TO PLAN TO

PROVIDE FULL PROGRAM ACCESS. THERE IS NOT

ONE SIZE FITS ALL CURRICULUM OR ONE SIZE

FITS ALL PROGRAMMING. SO, YOU REALLY NEED

TO THINK THROUGH WHEN CREATING ANY TYPE

OF PROGRAM, HOW YOU'RE GOING TO IMPLEMENT

IT WITH DIFFERENT POPULATIONS. I GOT AN

E-MAIL TODAY FROM A CIL ASKING HOW WE IMPLEMENT

OUR PRE-EMPLOYMENT TRANSITION TO STUDENTS

WHO ARE IN SELF-CONTAINED CLASSROOMS. WELL,

WE USE THE SAME CONTENT. WE JUST ADAPT IT

TO BE ABLE TO REACH THEM AND THAT'S VERY

SIMPLE TO DO. I KNOW WE TALKED A LITTLE BIT

ABOUT FRAGRANCE FREE AND SMOKE-FREE. WE HAVE

SIGNAGE IN OUR OFFICE THAT TALKS ABOUT FRAGRANCE

FREE. WE ALSO MAKE SURE IF WE HAVE ANY SMOKERS

ON OUR STAFF, THAT THEY HAVE AN AREA THAT THEY

CAN SMOKE THAT IS AWAY FROM A LOT OF OUR STAFF.

WE HAVE A LOT OF STAFF WITH ACTUAL CHEMICAL

SENSITIVITIES. SIGNAGE FOR PUBLIC AREAS THAT

MEETS ADA REQUIREMENTS. SO, IF YOU HAVE SIGNAGE,

MAKING SURE IT IS EITHER BRAILLE OR THE RAISED

LETTERING ON THE SIGNAGE, SO PEOPLE CAN READ IT.

AND THEN ALSO JUST ADVOCACY TO ACHIEVE PUBLIC

ACCESS AND THAT'S GOING TO BE A LOT OF WHAT

BRUCE TALKS ABOUT.

BRUCE DARLING: SO, ADVOCACY IS A PLANNED ACTION

TO SUPPORT AN ISSUE, INTEREST, CAUSE OR IDEA.

SO, I WANT TO EMPHASIZE THAT IT'S PLANNED.

IT'S NOT SOMETHING WE JUST RANDOMLY DO.

WE HAVE TO ACTUALLY THINK THROUGH WHEN WE'RE

ADVOCATING ON SOMETHING, HOW WE'RE GOING

TO DO IT AND WHAT WE WANT TO ACCOMPLISH.

SOMETIMES IT MIGHT LOOK A LITTLE MORE CHAOTIC

FROM THE OUTSIDE, BUT IT REALLY IS SOMETHING

YOU NEED TO HAVE THOUGHT THROUGH AND PLANNED.

IT ADDRESSES A POWER INEQUALITY. LET'S THINK

ABOUT IT. IF YOU HAVE A TON OF POWER,

YOU USE IT AND DO WHATEVER YOU WANT.

YOU DON'T NEED SOMEONE TO HELP YOU ADVOCATE FOR THAT.

SO, WHAT WE'RE DOING IS HELPING PEOPLE WHO BASICALLY

HAVE BEEN DISENFRANCHISED IN SOME WAY OR ANOTHER

AND WE NEED TO ACTUALLY PUSH BACK ON THE

POWER STRUCTURE. AND I HAVE ADDED A POINT—

ADVOCATES MUST BE AWARE OF THE CONSTITUTIONAL

RIGHTS OF PEOPLE WITH DISABILITIES AND

ASSERT THEM. THIS GOES BACK TO MY FIRST ILRU

TRAINING WHEN WE WERE TALKING ABOUT COMMUNITY INTEGRATION

AND TRANSITIONING FOLKS INTO THE COMMUNITY.

I CO-PRESENTED WITH KIRK LOWERY, WHO IS

AN ATTORNEY, WHO DID AN EXCEPTIONAL PRESENTATION

ABOUT CONSTITUTIONAL RIGHTS AND HOW WHAT

WE'RE TALKING ABOUT IN TERMS OF RIGHTS OF

CITIZENS REALLY GOES RIGHT BACK TO THE CONSTITUTION.

YOU WILL HAVE NOTICED IN SOME OF THE NATIONAL

ADVOCACY AROUND COMMUNITY INTEGRATION THAT

WE ARE STARTING TO TALK ABOUT THE CONSTITUTIONAL

RIGHTS OF INDIVIDUALS WITH DISABILITIES. SO

SOME OF THAT REFRAMING THINK ABOUT IT IN TERMS

OF COMMUNITY INTEGRATION. DOES THE STATE HAVE

THE RIGHT TO LOCK YOU UP FOR NO REASON? DO THEY

NEED A GOOD REASON TO LOCK YOU UP? DO THEY

NEED A REALLY GOOD REASON? THERE'S A STANDARD

THERE. NOW, I'M NOT SAYING PEOPLE DON'T GET

LOCKED UP FOR NO GOOD REASON. TRUST ME.

THIS IS THE WORLD WE LIVE IN AND OBVIOUSLY

THERE IS A LOT OF ADVOCACY AROUND THESE TYPES OF

THINGS -- LOCKED UP IN MANY DIFFERENT SITUATIONS.

AND IT'S REALLY INTERESTING WHEN YOU START TO

LOOK AT SOME OF THE ISSUES AROUND FOR-PROFIT

PRISONS AND HOW THOSE LOOK A LOT LIKE NURSING

FACILITIES IN TERMS OF STRUCTURES.

SO ANYWAY, THE CONSTITUTIONAL FRAMEWORK –

THINK ABOUT IT. THERE IS NO ASTERISK IN THE

CONSTITUTION THAT SAYS UNLESS YOU'RE TOO DISABLED.

SO, LET'S THINK THROUGH WHEN WE'RE TALKING ABOUT

THESE ISSUES COMING BACK TO CORE CONCEPTS OF

THIS IS THE CONSTITUTION. IT SAYS WE HAVE

THE RIGHT TO LIFE, LIBERTY, THAT TYPE OF THING.

LOCKING US UP DEPRIVES US OF THAT. SO, THINK ABOUT

REFERENCING THE CONSTITUTION. INDIVIDUAL ADVOCACY.

AS I SAID, SOMETIMES WE'RE DISREGARDED. IT DOES

HAPPEN TO ALL OF US AND IT'S NICE TO HAVE SOMEONE

WHO CAN HELP ADVOCATE WITH YOU AND FOR YOU.

HONESTLY, I'M PRETTY LOUD AND WHAT HAVE YOU,

SO I FEEL LIKE I KNOW HOW TO ADVOCATE FOR MYSELF.

BUT WE DID SOME WORK ON OUR HOUSE AND GOT

INTO A BIT OF A SCUFFLE WITH THE TOWN OVER

WHAT WE WERE DOING. IT MADE A LOT OF SENSE

TO HAVE SOMEONE WHO UNDERSTOOD WHAT THOSE RULES WERE

AND HOW THAT SYSTEM WORKED, WHO COULD ACTUALLY HELP

GUIDE US THROUGH THAT PROCESS. AND AT A OF COUPLE POINTS,

HE DID TURN TO ME – WASN’T VERY INDEPENDENT LIVING –

AND SAY, BRUCE SHUT UP. LET ME HANDLE THIS.

I AM THE ONE WHO IS PAID TO DO THIS.

AND HONESTLY, THE TOWN WAS ACTUALLY HAVING A FIT

BECAUSE OUR HOUSE WAS ACCESSIBLE. AND THEY

WANTED A PROVISION, THAT I WOULD SIGN OFF,

THAT WE COULD DO THE MODIFICATIONS AND THAT

THE HOUSE WOULD NEVER BE TURNED INTO A GROUP HOME.

I WAS LIKE, THIS IS ALL ABOUT “THEM” ISN’T IT. THEY

DON'T WANT DISABLED PEOPLE IN THE TOWN.

HE'S LIKE SHUT UP. DO YOU WANT YOUR HOUSE

TO BE A GROUP HOME? I SAID NO. BUT STILL.

SO, SOMETIMES A THOUGHTFUL PERSPECTIVE FROM

SOMEONE, WHO'S NOT IN THE MIDDLE OF IT, CAN

HELP GUIDE US THROUGH AND NAVIGATE SOME OF THESE

SYSTEMS. SO, WHEN YOU'RE DOING THIS, IT'S

IMPORTANT TO LISTEN TO THE CONSUMER. WE

START OUT, I WAS VERY CLEAR IN THE CONVERSATION

WHAT I WANTED TO HAVE HAPPEN. WHEN WE TALK TO

FOLKS, WE LISTEN TO THEM. WE HEAR WHAT THEY'RE SAYING.

SOMETIMES WE PAY ATTENTION TO WHAT THEY'RE NOT

SAYING AS WELL. SO, WE CAN ASK SOME QUESTIONS

AND GET A FEEL FOR THINGS. AND WE NEED TO BE

ABLE TO LISTEN TO THESE THINGS MORE THAN ONCE

AND RECOGNIZE THAT SOMETIMES THEY MAY NOT

GIVE ALL THE RELATIVE INFORMATION IN THE FIRST

ROUND OR THAT INFORMATION MAY CHANGE AND SHIFT.

THAT'S JUST HOW PEOPLE ARE. THERE ARE SOME PEOPLE

WHO -- IN OUR CENTERS -- WHO GET FRUSTRATED WHEN

PEOPLE'S STORY SHIFTS OR INFORMATION IS A

LITTLE DIFFERENT AND I SAY YOU KNOW WHAT,

ALL OF US DO THIS. IT'S NOT SOMETHING --

IT'S CALLED BEING HUMAN. MAYBE AT A GIVEN POINT

YOU'RE MORE FOCUSED ON ONE THING THAN ON ANOTHER.

YOU KNOW, MAYBE A DETAIL SHIFTS OR SOMETHING.

YOU WORK WITH PEOPLE WITH ALL TYPES OF DISABILITIES.

MOVE ON. JUST FIGURE OUT YOUR BEST APPROACH WITH IT.

IT IS IMPORTANT TO LISTEN AND FOLLOW THE CONSUMER'S

LEAD. WHEN WE'RE DOING INDIVIDUAL ADVOCACY,

THE ROLE OF THE ADVOCATE IS WE'RE GOING TO

GATHER ALL THE FACTS AND BE NONJUDGMENTAL.

SO, I THINK IT IS REALLY IMPORTANT IN ALL OF OUR

WORK TO NOT BE JUDGMENTAL ABOUT THE SITUATIONS

PEOPLE FIND THEMSELVES IN. AND ONE OF THE THINGS

I LIKE TO DO IS SELF-DISCLOSE. YOU KNOW WHAT,

SOMETIMES PEOPLE HAVE ISSUES WITH MONEY, CREDITORS,

WHAT HAVE YOU. WE DO A LOT OF THIS AROUND NURSING

FACILITY TRANSITION. JUST BECAUSE YOUR MONEY WAS

SCREWED UP AND A BILL DIDN'T GET PAID, DOESN'T MEAN

YOU'VE GIVEN UP ALL OF YOUR RIGHTS TO COMMUNITY INTEGRATION.

IT'S LIFE AND I'M VERY CLEAR. I DON'T CARRY A LOT

OF CASH WITH ME, BECAUSE IF IT’S IN MY POCKET, IT GETS

SPREAD AROUND. I'VE NOT BEEN -- I HAVE BAD MODELS

FROM MY OWN PERSONAL CHECKBOOK. THAT'S WHY

I DON'T HANDLE THE CENTER'S MONEY EVER. JUST

BECAUSE PEOPLE HAVE WEAKNESSES, DOESN'T MEAN

THEY DON'T HAVE STRENGTHS. AND IF YOU'RE CLEAR

IN YOURSELF TO DISCLOSE SOME OF THAT, YOU'RE

GIVING PEOPLE A SENSE OF IT'S SAFE TO SHARE THAT.

NOW I’LL TELL YOU, THIS DOESN'T WORK SO WELL

IN MY PERSONAL RELATIONSHIP. MY HUSBAND WOULD

LIKE ME TO BE BETTER WITH CERTAIN THINGS AND

I OFTEN REMIND HIM THIS IS A NO JUDGMENT ZONE.

AND HIS RESPONSE IS TO WAVE HIS HAND AT ME AND SAY

YES, THIS IS A NO JUDGMENT ZONE, BECAUSE THERE

IS NO JUDGMENT, WHICH I THINK IS REALLY VERY FUNNY.

AND IT DOES ACTUALLY -- WELL, THERE YOU GO.

HE'S STILL MARRIED TO ME. HE'S NOT GIVEN UP ON IT,

SO THERE MUST BE SOMETHING IN IT FOR HIM.

BUT REALLY THE WHOLE SENSE OF, YOU KNOW, WE'RE

NOT GOING TO JUDGE YOU FOR WHAT IT REALLY IS.

WHETHER THE INFORMATION'S CORRECT OR NOT.

WHETHER YOU HAD SOME PART IN THIS. OUR JOB HERE

IS TO FIGURE OUT THE PATH FORWARD FOR YOU.

IDENTIFY APPROACHES TO ADDRESS THE PROBLEM AND

ASSIST THE CONSUMER IN SORTING THROUGH THE OPTIONS.

NOW, THIS IS REALLY IMPORTANT. THERE ARE LOTS

OF DIFFERENT WAYS TO ADDRESS SITUATIONS WHEN YOU'RE

DOING INDIVIDUAL ADVOCACY SO YOU KNOW, IT MIGHT

BE VERY EASY FOR YOU TO SAY ALL RIGHT. HERE'S WHAT

WE'RE GOING TO DO. WE'RE GOING TO WRITE A LETTER

AND HANDLE IT THIS WAY OR WE'RE GOING TO APPEAL

IT IN THIS MANNER. THERE ARE A NUMBER OF DIFFERENT

APPROACHES. GIVING THE CONSUMER THE OPTION TO

CHOOSE WHICH APPROACH, REINFORCES THAT THEY'RE

IN CONTROL OF THEIR LIFE. THAT YOU'RE DIFFERENT.

IT MAY TAKE A LITTLE MORE TIME, BUT THERE MAY BE

VALID REASONS. MAYBE THEY DON'T WANT TO GO

THROUGH A PARTICULAR PROCESS. GIVE THEM AN

OPPORTUNITY TO MAKE SOME OF THOSE CHOICES

RATHER THAN JUST MAKE THE CHOICES FOR THEM

AND POTENTIALLY PUSH THEM OUT. PROVIDE

INFORMATION AND SUPPORT TOWARD THE CONSUMER'S

EMPOWERMENT. IT'S REALLY IMPORTANT.

INFORMATION. SOMETIMES WE HAVE TECHNICAL

INFORMATION THAT PEOPLE REALLY NEED AND CAN USE.

AND NOT ALL OF US HAVE ALL THE TECHNICAL

INFORMATION OUT THERE. SO, WHEN PEOPLE

COME TO ME AND THEY SAY, I HAVE A

BENEFIT'S PROBLEM. I WANT TO KNOW HOW TO

DEAL WITH THIS AND THEY START TALKING THROUGH,

I LISTEN POLITELY AND I SAY NOW WE'RE GOING

TO TAKE YOU TO OUR BENEFITS PEOPLE,

BECAUSE THEY KNOW THE INS AND OUTS OF THIS

WAY BETTER THAN I DO. BECAUSE THERE ARE

A LOT OF TECHNICAL RULES AND THEY CAN BE

VERY HELPFUL THERE. SO, I THINK KNOWING

WHAT YOU KNOW, KNOWING WHAT YOU DON'T KNOW,

AND KNOWING WHO KNOWS THE TECHNICAL INFORMATION

IS REALLY IMPORTANT. BUT THAT SUPPORT IS

ALSO IMPORTANT. BECAUSE HONESTLY, THE KINDS OF ISSUES

PEOPLE ARE DEALING WITH, THEY NEED TO HAVE

A SENSE OF EMPATHY. AND I THINK WE'VE TALKED

ABOUT THAT IN OTHER PRESENTATIONS. PROVIDING

REFERRALS AND LINKAGES TO OTHER OPTIONS INCLUDING

EXPERTISE. SO, YEARS AGO, I THINK I GOT THE

DISTINCTION OF BEING THE MOST LITIGIOUS SERVICE

COORDINATOR OR CASE MANAGER BECAUSE I KNEW

LEGAL ASSISTANCE PEOPLE. I COULD IDENTIFY CASES.

AND VIRTUALLY EVERYONE I WAS ASSISTING IN

THE ORGANIZATION HAD SOME KIND OF LAWSUIT

THAT THEY WERE ENGAGED IN. BUT THERE WERE LOTS

OF BAD THINGS THAT WERE HAPPENING IN ROCHESTER

AT THE TIME. DISABLED PEOPLE WERE BEING SCREWED ALL OVER

THE PLACE. WE WERE ACTUALLY FIGHTING AGAINST

THAT. KNOWING WHO TO GO-- THOSE THE LINKAGES

AND PIECES -- AND HAVING A SENSE OF WHAT THE

RIGHTS ARE SO YOU CAN TELL PEOPLE YOU KNOW

WHAT? THAT'S NOT FAIR, THAT'S WRONG AND

WE CAN WORK ON THIS TOGETHER. TEACHING

SELF-ADVOCACY SKILLS. SO, IT CAN BE REALLY

INTIMIDATING IN A MEETING WHERE YOU'VE GOT

POWERFUL PEOPLE, WHO ARE BASICALLY PEOPLE

WHO HAVE POWER OVER YOU, WHO ARE GOING

TO TELL YOU HOW YOU'RE SUPPOSED TO LIVE YOUR

LIFE. SOMETIMES PEOPLE HAVE THE CHUTZBAH TO BE

ABLE TO JUST DO THESE THINGS AND CALL IT OUT.

OFTENTIMES, NOT SO MUCH. SOMETIMES WHAT I

HAVE FOUND IS, WHAT THE PERSON REALLY WANTED

WAS SOMEONE TO GRAB ON TO THEIR HAND.

I WAS IN A DISCHARGE PLANNING MEETING

WHERE BASICALLY A WOMAN FROM OUR CENTER

I'VE KNOWN FOR MANY YEARS -- THEY WERE

TRYING TO FORCE HER INTO AN INSTITUTION

AND JUST AS THE SOCIAL WORKER STARTED

THE MEETING, SHE REACHED OVER AND SHE

GRABBED MY HAND. SHE WAS 80 YEARS OLD

AND HAD CEREBRAL PALSY. SHE HAD A HAND GRIP

STRENGTH I COULD NOT BELIEVE. BUT SQUEEZING

THE BLOOD OUT OF MY FINGERS WAS REASSURING

TO HER AND IT GAVE US A SENSE OF CONNECTION.

AND I THINK THAT PIECE OF SUPPORT AND BEING

THERE WAS HELPFUL. AND WHEN SHE -- WHEN THE

SOCIAL WORKER TRIED TO BASICALLY PLAY A GAME,

HAVING ME THERE TO BE ABLE TO SUPPORT HER

AND SAY WELL, THAT'S NOT REALLY THE QUESTION

WE SHOULD BE ASKING, WHEN THEY SAID NOW SURELY

YOU KNOW YOU NEED TO GO INTO THE INSTITUTION.

HOW DO WE MAKE THAT HAPPEN? SHE SQUEEZES EVEN

MORE AND I BASICALLY REDIRECT THE CONVERSATION

AND HELP US GET TO WHERE WE NEED TO BE.

AND SOMETIMES IT CAN JUST BE PUTTING UP A FIGHT

IN THIS CONVERSATION IS ALL YOU NEED BECAUSE

IN THE END THE RESULT FROM THIS ONE WAS BEING

DIFFICULT AND NOT CAVING IN, PUSHED THE MEETING,

BECAUSE IT WAS AN AFTERNOON ON A FRIDAY.

AND TO THE POINT WHERE FOLKS WERE LIKE IT'S

A SHIFT CHANGE AND WE NEED TO GO. WHICH BOUGHT

SURELY ENOUGH TIME, BASICALLY, TO GET A LITTLE

HEALTHY AND AVOID NURSING HOME PLACEMENT ALTOGETHER.

BUT THAT KIND OF THING -- KNOWING HOW TO RUN OUT

THE CLOCK AND THAT TYPE OF THING -- THAT CAN BE

VERY, VERY HELPFUL.

FOLLOW THE CONSUMER'S LEAD AND KNOW HOW MUCH

ASSISTANCE IS NEEDED. THAT'S REALLY IMPORTANT, BUT

I THINK ENTIRELY IT’S FOLLOWING THE PERSON’S LEAD.

PROVIDE AN OBJECTIVE INSIGHT INTO THE SITUATION.

THIS IS WHERE WE CAN BE VERY HELPFUL TO FOLKS.

WHEN YOU'RE IN THE MIDDLE OF YOUR OWN STUFF,

YOU DON'T NECESSARILY HAVE A SENSE OF WHAT

DIRECTION TO GO AND BEING ABLE TO SAY TO SOMEONE,

YOU KNOW, I'VE HAD THIS KIND OF FIGHT. I'VE NOT WON

THIS ISSUE THIS WAY BEFORE. HERE ARE SOME

OPTIONS THAT WE HAVE. BUT BEING ABLE TO HAVE

THAT CONVERSATION AND SHARE THAT. AND IF YOU

DEVELOPED A SENSE OF TRUST AND A RAPPORT

WITH THE INDIVIDUAL, THAT GOES A LONG WAY.

IF YOU HEARD THEM, YOU CAN THEN PROVIDE THAT

KIND OF FEEDBACK, EVEN IF IT'S NOT EXACTLY WHAT

THEY WANT TO HEAR. IF THEY KNOW YOU HAVE A

HISTORY OF SAYING YOU KNOW WHAT, THAT IS JUST

SCREWED UP. WE'RE GOING FIGHT THIS ONE AND

FIGHT IT TILL THE END, THEY KNOW YOU'RE WILLING

TO DO THAT WITH THEM. THEY CAN THEN HEAR --

WHEN THE CENTER HAS BEEN VERY SUPPORTIVE TO

FOLKS -- WHEN YOU FIND A PLACE YOU REALLY

CAN'T MOVE SOMETHING EASILY, THEY CAN HEAR THAT.

PROVIDE MEDIATION RESOURCES AND NEGOTIATE ON

THE CONSUMER'S BEHALF, IF REQUESTED.

CREATE A PARTNERSHIP SO THE CONSUMER NEVER

FEELS ALONE IN THE PROCESS. I THINK THAT

GOES BACK TO CHECKING IN. WHEN WE'RE DOING

THESE KINDS OF MEETINGS AND THINGS,

I LIKE TO TALK WITH THE INDIVIDUAL BEFORE

THE MEETING AND WE GO, WE HAVE MEETING –

FIGHT, WHATEVER YOU WANT TO CALL IT. THEN DEBRIEF

AFTERWARD. I THINK THAT KIND OF CONNECTION

HELPS THE PERSON PROCESS WHAT HAPPENED

AND HELPS YOU GET A FEEL FOR WHETHER YOU'RE

DOING THE RIGHT THING. NEVER TAKE NO AS

THE ANSWER. I HAVE A BIT OF A REPUTATION

IN MY CENTER AS BEING A BULLDOG, SO WHEN I’VE

DECIDED THAT WE'RE GOING TO DO SOMETHING,

WE'RE GOING TO DO IT. AND I DON'T LIKE PEOPLE

-- I HAVE A STRONG SOCIAL JUSTICE CORE -- I DON'T

LIKE PEOPLE BEING SCREWED BY POWER. JUST DON'T

LIKE IT. SO, WE WILL DIG OUR HEELS IN.

SO, BUT NEVER TAKE NO -- I WAS TALKING TO RODNEY

EARLIER. I SAID EVERYTHING YOU NEED TO KNOW,

YOU CAN LEARN IN AN ADAPT ACTION.

SOME STRATEGIES, WE SAY IN ADAPT,

“WATER AROUND A ROCK”. SO, IF THIS IS A

BLOCK, GO AROUND IT AND IF A SITUATION SEEMS

TO BE STUCK, ESCALATE. SO, I'M GOING GIVE A

QUICK EXAMPLE OF SOMEONE WE WORKED WITH

WHERE WE USED SOME OF THESE STRATEGIES.

RICHARD IS A GENTLEMAN. HE HAS ESSENTIALLY A

COGNITIVE DISABILITY, ALTHOUGH IT'S VERY –

I DON'T KNOW. I DIDN'T REALLY ACTUALLY NOTICE

MUCH OF IT. HE HAPPENED TO BE VERY PHYSICALLY

ABLE. SO, FROM MY PERSPECTIVE, HE WALKED AROUND

FINE. HE WAS IN A NURSING FACILITY AND I HONESTLY

COULD NOT FIGURE OUT HOW THIS MAN ENDED UP

IN A NURSING FACILITY. BUT WE ENDED UP – WE

HELPED SUPPORT HIM AND HE GOT OUT, HELPED HIM

GET AN APARTMENT AND HE WAS LIVING OUT IN

THE COMMUNITY. HE ENDED UP NEEDING TO GO TO

THE HOSPITAL FOR SOMETHING AND THE HOSPITAL

DECIDED THAT HE NEEDED TO GO INTO THE NURSING

FACILITY AGAIN. AND RICHARD WAS REALLY CLEAR.

I'M NOT DOING THAT. AND WE GAVE HIM SOME

SUGGESTIONS. JUST TELL THEM NO. THEY CAN'T

FORCE YOU INTO A NURSING FACILITY, YOU KNOW.

SO, THEY TRIED TO CONVINCE HIM THAT THAT'S

WHAT HE WANTED. SO, APPARENTLY ONE NIGHT

THEY CAME INTO HIS ROOM AND THEY SAID WE'RE

DISCHARGING YOU. SIGN THESE PAPERS AND WE'RE

GOING SEND YOU, AND I DON'T KNOW WHETHER THEY

DELIBERATELY LIED, OR WHETHER THEY JUST SORT

OF SKATED OVER DETAILS OR WHAT HAVE YOU, AND

HE MADE THE ASSUMPTION HE WAS GOING HOME. SO,

THEY PUT HIM IN THE AMBULANCE IN THE MIDDLE OF

THE NIGHT AND HE SEES THE AMBULANCE IS DRIVING

TOWARDS HIS HOUSE AND HE'S THINKING ALL IS GOOD.

AND THEN THEY DRIVE PAST HIS HOUSE AND DRIVE HIM

TO A NURSING FACILITY. AND HE'S ADMITTED.

OKAY. NOW, FIRST I WANT TO GIVE THIS MAN CREDIT.

IF I WAS IN A VEHICLE AND SOMEONE WAS DRIVING ME

PAST MY HOUSE TO LOCK ME UP, I WOULD COMPLETELY –

EVEN WITH MY COMMITMENT TO NON-VIOLENCE, I WOULD

HAVE COMPLETELY LOST IT IN THE BACK OF THAT

VEHICLE AND SOMEONE WOULD BE STRANGLED AND

THERE WOULD BE AN ACCIDENT. HE DIDN'T DO THIS.

HE STAYED REALLY CALM, COOL, COLLECTED THROUGH

THE WHOLE PROCESS. CALLED US THE NEXT DAY

AND SAID THEY'VE LOCKED ME UP. I'M LIKE WHAT?

SO, WE CHATTED WITH HIM. HE DIDN'T NEED A LOT OF

ASSISTANCE. VERY LITTLE PHYSICAL ASSISTANCE.

SO, AFTER HE WAS THERE A LITTLE BIT AND THINGS

WEREN'T MOVING AND NO ONE SEEMED TO BE INTERESTED

IN SENDING HIM HOME, HE CALLED HIS BROTHER UP

AND SAID BRING THE CAR OVER. HIS BROTHER CAME OVER,

PICKED HIM UP AND TOOK HIM HOME. THERE YOU GO.

PROBLEM SOLVER. BUT HE WAS DIABETIC. HE NEEDED

SOME SERVICES, BUT HE NEEDED MEDICATION. THE

NURSING FACILITY NOTIFIED -- HE DIDN'T HAVE MEDS

BECAUSE HE HAD BEEN IN THE HOSPITAL. HE WAS DIABETIC.

HE NEEDED MEDICATION. IT WAS NOT SOME CASUAL

THING AND THE NURSING FACILITY CALLED THE PHARMACY

AND SAID DO NOT FILL HIS PRESCRIPTIONS.

HE LEFT THE NURSING FACILITY AGAINST MEDICAL

ADVICE. NOW, I’LL JUST POINT OUT THAT THIS IS

OVER MARTIN LUTHER KING WEEKEND. THE CLINIC

THAT HE WAS GETTING HEALTH SERVICES THROUGH

BECAME A PARTY TO THIS. THE LINE STAFF PERSON

WHO WAS INVOLVED JUST WAS LIKE, OH, MY GOD,

THIS IS BEYOND ANYTHING I CAN HANDLE. SHE GOT

HER SUPERVISOR INVOLVED. HER SUPERVISOR WAS

WORKING WITH HER IN THIS AND THEN SHE REALIZED

OH, MY GOD, THIS IS ESCALATING. I CAN'T DEAL

WITH THIS. SHE GETS THE DIRECTOR INVOLVED.

THEY ESCALATE A MEETING. NOW THEY'VE MET WITH

THE DOCTOR, THE MEDICAL DIRECTOR AT THE CLINIC,

WHO IS BASICALLY PRETENDING THEY DIDN'T HAVE

A MEDICAL APPOINTMENT, AND THEY'RE SAYING --

SHE BRINGS IN A SECOND DIRECTOR. SO NOW I'VE

GOT TWO OF MY DIRECTORS, SUPERVISOR, LINE STAFF,

EVERYONE'S WORKING ON THIS AND THEY HAVE HIT

A BRICK WALL. THEY CALL ME. THEY SAY YOU KNOW

WHAT, HERE'S WHERE WE'RE AT. WE'VE DONE ALL OF

THESE THINGS. WE'RE GOING TO CONTINUE TO DO THIS.

DO YOU HAVE ANY SUGGESTIONS? I SAID, I'LL

CALL THE CEO. SO, I START THAT PROCESS.

I AM STUNNED WHEN THE CEO (NOT SO MUCH, I

SUPPOSE) BACKS THE MEDICAL DIRECTOR, WHO BACKS

THE DOCTOR. OH, BY THE WAY, THE WAY MY PROGRAM

DIRECTOR DESCRIBED IT, SHE SAID THIS DOCTOR –

IT'S LIKE THIS DOCTOR AND THIS CONSUMER WENT

THROUGH A BAD DIVORCE. HE'S CARRYING SO MUCH

BAGGAGE. HE'S BRINGING UP THINGS THAT HAPPENED

10 YEARS AGO. LIKE YOU SLEPT AT A PERSON'S HOUSE.

AND, SHE'S LIKE HE HAS AN APARTMENT. GET OVER IT.

CLEARLY, THERE'S A LOT GOING ON. BUT IN THE END,

BASICALLY, WHEN I GOT NOWHERE WITH THE CEO,

I STARTED CALLING BOARD MEMBERS. JUST TO SAY

JUST SO YOU KNOW, HERE'S THE SITUATION.

IT'S MARTIN LUTHER KING WEEKEND. THIS IS THE

ANTHONY JORDAN HEALTH CENTER. ANTHONY JORDAN

WOULD BE ROLLING OVER IN HIS GRAVE, IF HE KNEW

WHAT YOU WERE DOING TO THIS MAN. SERIOUSLY, YOU

NEED TO THINK ABOUT THIS. AND EVENTUALLY

WE WERE ABLE -- WORKING WITH THE INDIVIDUAL -- TO

FIND A PATH FORWARD. I WANT TO GIVE HIM A LOT

OF CREDIT. THROUGHOUT THIS ENTIRE PROCESS,

HE MADE LOTS OF REALLY AMAZING CHOICES IN

NAVIGATING THROUGH THAT. BUT EVEN IF HE DIDN'T,

SERIOUSLY I WOULD HAVE SAID YOU KNOW WHAT,

I'M FINE WITH IT, BECAUSE HE REALLY WAS PUT IN

TERRIBLE SITUATIONS. I WAS THINKING ABOUT THE

TRAUMA ISSUE AND THE THINGS THAT WE DEAL WITH

AND ONE OF THE THINGS THAT STRUCK ME IN THIS

STORY WAS HOW EVERYONE KEPT ESCALATING THE ISSUE

AND WE ALL STOOD TOGETHER. IN THE END, ACTUALLY,

HOW RICHARD DESCRIBED US -- HE DESCRIBED US

AS HIS POSSE. SO, HE TOLD THE SOCIAL WORKER,

YOU KNOW, MY POSSE IS COMING. AND WE WERE PART

OF HIS TEAM AND THAT REALLY MADE A DIFFERENCE

FOR HIM.

SO, MOVING FROM THE INDIVIDUAL AND HOW WE'RE

HANDLING INDIVIDUAL ADVOCACY, LET'S TAKE A

LOOK AT SYSTEMS ADVOCACY. SO ASIDE FROM BEING

A REQUIRED CORE FUNCTION OF CENTERS -- SO IT'S

REQUIRED, THAT'S WHY WE SHOULD DO IT.

BUT IF WE DON'T FIGHT FOR OUR OWN RIGHTS, LET'S

BE REAL, NO ONE ELSE IS GOING TO DO THIS FOR US.

AND YOU KNOW, I THINK IT'S IMPORTANT THE KINDS

OF INJUSTICE THAT WE FACE COLLECTIVELY AND THEN

WHEN YOU LOOK BEYOND JUST INJUSTICE AROUND THE

DISABILITY COMMUNITY, HOW MULTIPLY MARGINALIZED

COMMUNITIES FACE MULTIPLE FORMS OF INJUSTICE

AND HOW NO ONE IS GOING TO BASICALLY STEP UP.

WE HAVE TO FIGHT TOGETHER ON THESE THINGS.

AND PERSONALLY, I BELIEVE WE HAVE AN OBLIGATION

TO MAKE THE WORLD BETTER FOR OTHERS.

VERY EARLY IN MY LIFE, I CAME TO THE POINT –-

I HAD A QUESTION, WHAT ARE YOU DOING WITH

YOUR TIME HERE?

SO, RATHER THAN WAIT UNTIL I WAS OLDER TO

THINK ABOUT THAT, I WAS HAVING THESE THOUGHTS

AND THESE QUESTIONS WHEN I WAS IN MY 20S. AND I

DECIDED I NEEDED TO USE MY TIME TO ACCOMPLISH

SOMETHING. MAKE SOME KIND OF DIFFERENCE, AS

OPPOSED TO JUST SORT OF HAVING A GOOD TIME AND

MOVING ON. AND FRANKLY, WE GET TO BE -- IT'S

A PRIVILEGE TO BE THE VOICE FOR PEOPLE WHO CANNOT

YET BE THEIR OWN VOICE. AND I THINK THAT'S –

WHEN YOU LOOK AT SOME OF THE THINGS THAT WE'VE

WORKED ON, IT'S REALLY SUPPORT. FOR ME,

PERSONALLY, OUR CENTER HAS IDENTIFIED FOLKS

WHO HAVE THE LEAST VOICE TO HELP THEM.

SO, FOLKS WHO ARE LOCKED UP IN INSTITUTIONS,

FOLKS WHO ARE DEAF-BLIND, WHO CAN'T ACCESS

THE COMMUNITY AT ALL. THESE ARE THE FOLKS

THAT WE GO OUT OF OUR WAY TO SUPPORT, BECAUSE

FRANKLY, NO ONE ELSE IS GOING TO DO THAT. SO,

FRAMING IS EVERYTHING. WHEN I STARTED IN

INDEPENDENT LIVING, OUR IL ADVOCATE WOULD TALK

ABOUT THE CONFLICT BETWEEN SERVICE DELIVERY,

INDIVIDUAL ADVOCACY AND SYSTEMS ADVOCACY. HE SAID,

I DON’T KNOW. I CAN'T FIGURE OUT HOW TO BALANCE MY TIME.

I CAN PUT MY ENERGY INTO INDIVIDUAL ADVOCACY, BUT THEN

I DON'T HAVE TIME TO DO SYSTEMS ADVOCACY. IF I'M

DOING SYSTEMS ADVOCACY, I'M NOT HELPING INDIVIDUALS.

AND IT WAS HIS FRAMING ON THIS THAT HAD ME THINKING

WELL, THERE'S A CHOICE HERE WE HAVE TO MAKE. AND

THEN, I STARTED WORKING IN A CHILDREN'S ADVOCACY

ORGANIZATION AND CHILDREN'S ADVOCACY ORGANIZATIONS

DID INDIVIDUAL ADVOCACY, BUT THE POINT OF THE

INDIVIDUAL ADVOCACY WAS TO GET TO THE SYSTEMS ISSUES

AND ACTUALLY IDENTIFY WHAT THEY WERE, SO THOSE ISSUES COULD BE

ADDRESSED. SO, THERE ARE THINGS THAT DIRECT SERVICES

CAN DO. THEY CAN IDENTIFY BARRIERS AND DO SYSTEMS ADVOCACY

TO REMOVE THEM. I THINK WE TALKED INITIALLY -- IT WAS

IN THE I&R – I THINK DARREL'S PRESENTATION WHERE HE

IDENTIFIED HOW YOU CAN SEE IN THE ISSUES THAT COME

UP IN YOUR I&R QUESTIONS. YOU CAN TREND ON THAT AND

LOOK TO DO SYSTEMS ADVOCACY. YOU CAN HELP IDENTIFY

PEOPLE WHO CAN MAKE A CASE FOR CHANGE. SO, WHEN YOU

HAVE FOLKS, WHO ARE COMING IN WHO HAVE ISSUES THAT

YOU'RE DEALING WITH, YOU CAN BRING THEM TOGETHER.

YOU CAN FRAME INDIVIDUAL ISSUES IN TERMS OF A

SYSTEM BIAS, WHICH UNDERSCORES THAT THE PROBLEM IS IN

THE ENVIRONMENT, NOT THE PERSON. SO, I THINK IT'S HELPFUL

WHEN YOU'RE DOING YOUR INDIVIDUAL ADVOCACY TO POINT OUT

THIS ISN'T YOU. THIS IS THE SYSTEM. AND WE CAN HELP CHANGE

THE SYSTEM AND WE CAN SUPPORT INDIVIDUALS IN JOINING

OUR SYSTEMS ADVOCACY EFFORTS. OKAY. REALITY CHECK.

WHEN YOU'RE LIVING IN A GARAGE OR DON'T HAVE ENOUGH FOOD,

THAT'S NOT THE TIME YOU'RE GOING TO SPEND YOUR ENERGY

GOING TO A TOWN COUNCIL MEETING. IT'S JUST NOT GOING

TO HAPPEN. BUT THE IL TEAM WILL HELP EVENTUALLY FIND

A PLACE FOR YOU TO LIVE. THEY WILL HELP YOU GET FOOD

AND EVENTUALLY, YOU'LL GET TO PLACE WHERE YOU CAN

HAVE THOSE CONVERSATIONS AND BE A PART OF THAT. IT’S

HELPFUL TO LET PEOPLE – AND THEN, THE OTHER THING YOU

CAN DO, IS BE A PART OF THE TEAM THAT PROVIDES

PEER SUPPORT TO THE OTHER FOLKS WHO ARE GOING THROUGH THIS.

AND I HAVE FOUND -- IT'S KIND OF INTERESTING -- IT'S A

LITTLE COUNTER INTUITIVE – THAT SOMETIMES IT IS EASIER

FOR PEOPLE TO CHANGE THINGS OUT IN THE WORLD

BEFORE THEY CHANGE THEIR OWN SELF.

SO, SYSTEMS ADVOCACY ACTIVITY HAS ALLOWED PEOPLE --

MAYBE THEY DIDN'T FEEL THEY COULD LIVE ON THEIR OWN,

BUT THEY DID FEEL THEY COULD TORMENT THE TRANSIT AUTHORITY

RELENTLESSLY TO PUT LIFTS ON BUSES. AND IT WAS THROUGH THAT

THAT THEY DISCOVERED OH, I HAVE POWER. I CAN ACTUALLY CHANGE

THESE THINGS. IT REALLY DID WORK LIKE THIS AND

I FOUND THAT AMAZING.

HOW YOU ADDRESS SYSTEMS ADVOCACY. SO, I'M GOING TO QUOTE

BOB KAFKA WITH THE PITCHFORK. THERE'S A WHOLE DISPUTE

ABOUT HOW MANY PRONGS ARE IN A PITCHFORK. I'M NOT A

PART OF THAT, I COULDN'T REMEMBER ANY WAY, BUT IT'S

A THING. PUBLIC EDUCATION AND MEDIA. A LOT OF US

USE THAT. GET THE STORY OUT INTO THE PRESS;

GET THE PEOPLE TO KNOW THERE'S AN ISSUE.

LEGISLATIVE ADVOCACY. KIMBERLY IS GOING TO TALK

ABOUT LOBBYING SPECIFICALLY, BUT THAT IS A TOOL WE

CAN USE. WE'RE GOING TO TALK SPECIFICALLY ABOUT LOBBYING,

BUT THERE IS MORE TO LEGISLATIVE ADVOCACY THAN JUST

STRICTLY LOBBYING. YOU CAN EDUCATE PEOPLE ABOUT LAWS.

YOU CAN EDUCATE CONSUMERS. THEY CAN WEIGH IN.

THE JUDICIAL PROCESS. SO, PERSONALLY I HAVE TO SAY,

I HAVE NOT FOUND A LOT OF SATISFACTION IN DEALING WITH

THE COURTS AND THE LAWYERS, BUT WE HAVE DEFINITELY SUED

AS A CENTER AND SUPPORTED INDIVIDUALS IN LAWSUITS.

SO PROBABLY MOST NOTABLY, SUING THE LOCAL TRANSIT AUTHORITY,

WHICH MAY OR MAY NOT HAVE RESULTED IN 15 MILLION DOLLARS

BEING RIPPED OUT FROM OUR BUDGET. BUT IN THE END,

WE DID ACTUALLY SUCCESSFULLY SUE THE TRANSIT AUTHORITY

TO PROVIDE REQUIRED SERVICES THAT THEY WERE NOT PROVIDING.

THERE'S ADMINISTRATIVE AND EXECUTIVE ADVOCACY.

SO, THIS IS WHERE – ALL RIGHT. SO, YOU GET THE ALERT.

RESPOND TO THESE RULE CHANGES AT THE FEDERAL LEVEL

AND YOU THINK OH, GOD, I CAN'T POSSIBLY DO THIS.

IF WE'VE BEEN GOOD, WE'VE SENT YOU OUT SAMPLE THINGS

THAT YOU CAN JUST CHANGE THE NAME AND INCORPORATE STUFF

AND SEND THAT IN. THAT REALLY IS AN IMPORTANT FORM

OF ADVOCACY. TO ADVOCATE FOR THOSE RULE CHANGES.

AND THEN DIRECT ACTION. SO, PROBABLY ONE OF THE THINGS

I'M MORE KNOWN FOR IN TERMS OF ADVOCACY, I PERSONALLY

FIND IT INCREDIBLY -- UNLIKE LITIGATION -- I FIND

DIRECT ACTION MUCH MORE INTERESTING. THERE'S A CERTAIN

LEVEL OF IMMEDIATE GRATIFICATION IN THE PROCESS.

OF COURSE, IT IS WAY DELAYED GRATIFICATION, IF YOU GET

GRATIFICATION AT ALL.

ALL OF THESE PIECES THOUGH FIT TOGETHER. AND JUST BECAUSE

I LIKE ONE MORE THAN ANOTHER, DOESN'T MEAN I'M GOING TO

ONLY DO THE ONE THAT I LIKE. I USE ALL OF THE TOOLS.

TO BE PERFECTLY FRANK, GOING AND DOING HILL VISITS

ANNOYS ME. SO, TALKING TO -- AND NO OFFENSE TO THE

20-SOMETHINGS -- TALKING TO A 20-SOMETHING WHO HAS

NO EXPERIENCE ABOUT AN ISSUE, WHO TREATS ME LIKE

I'M LESS IMPORTANT THAN THE BUG ON THE BOTTOM OF HER

SHOE, IS NOT REALLY FUN. BUT IF I DON'T DO IT,

NO ONE ELSE IS GOING TO DO IT. OR, NO ONE ELSE

OUTSIDE OF OUR COMMUNITY IS GOING TO DO IT.

SO, IT IS PART OF ONE OF THE THINGS WE HAVE TO DO.

WHEN YOU'RE PUTTING THE PITCHFORK TO USE, IDENTIFY

WHAT THE ISSUE IS. OKAY. AND THAT REALLY IS –

WE CAN DO A WHOLE SESSION ON HOW TO CUT AN ISSUE

AND HOW TO FOCUS THAT, BUT IT REALLY IS -- AN

ISSUE IS NOT TRANSPORTATION. AN ISSUE IS THERE

ARE NO LIFTS ON BUSES IN ROCHESTER. IT'S CONCRETE,

IT’S IDENTIFIABLE. YOU CAN DESCRIBE IT.

SET GOALS. IN THAT CASE, WE'RE LIKE WE'RE GOING

TO PUT LIFTS ON BUSES. SEEMS PRETTY SIMPLE.

MAYBE NOT SO MUCH.

DEVELOP STRATEGIES AROUND THAT AND THEN

CELEBRATE THE SMALL SUCCESSES. EVEN THE SMALL ONES.

SO, IT'S IMPORTANT. ONE OF THE THINGS WHEN WE'RE

DOING ADVOCACY IS TO CELEBRATE THE THINGS THAT WE

ACCOMPLISH. SO, I THINK THAT'S ONE OF THE THINGS

THAT HELPS NOURISH OUR SOULS AS WELL. SO, WHEN WE'RE

STRUGGLING WITH THESE ISSUES, SUPPORTING EACH OTHER,

HAVING EVERYONE IN THE CENTER WILLING TO PITCH IN

WHEN THINGS GET TOUGH, AND CELEBRATING THE SUCCESSES

ARE REALLY WAYS THAT WE CAN HELP CREATE A SENSE

THAT THE CENTER IS DOING WHAT IT NEEDS TO DO.

AND, I’M GOING TO TURN IT OVER TO KIMBERLY FOR LOBBYING.

KIMBERLY TISSOT: ALL RIGHT, LOBBYING. WHOOHOO.

SO, ADVOCACY AND LOBBYING. THERE ARE VERY FINE LINES.

I'M GOING TO TALK A LITTLE ABOUT THAT, BUT I WANT TO

START OFF WITH SAYING WHY WE STARTED TO LOBBY.

SO, IN SOUTH CAROLINA, THERE'S A LOT OF REALLY BACKWARDS

LAWS. AND WE KEPT SEEING THIS THROUGH OUR INDIVIDUAL CASES.

PEOPLE WOULD COME IN AND CONTACT US ABOUT A PARTICULAR

SITUATION. AND THEN WE WOULD GO TO A STATE AGENCY,

AND SAY HEY, WHY DID YOU DO IT THIS WAY? AND THEY ARE

LIKE, WELL, WE FOLLOWED THE LAW. AND WE HAD TO DO A LOT

OF RESEARCH WITH THESE LAWS. SO, IF THEY'RE FOLLOWING

A LAW THAT AUTOMATICALLY DISCRIMINATES AGAINST PEOPLE

WITH DISABILITIES, THEN SOMETHING NEEDS TO CHANGE.

WE KEPT FORMING THESE RELATIONSHIPS WITH STATE AGENCIES

AND FORMING THESE RELATIONSHIPS WITH PROTECTION AND ADVOCACY.

I REMEMBER I WAS ON THE PHONE WITH SOMEBODY ELSE

AND I’M SAYING WHAT ARE WE GOING TO DO ABOUT THIS?

THEY'RE LIKE WHAT ARE YOU GOING TO DO ABOUT IT, KIMBERLY?

OH, SO, I'M TAKING THIS RESPONSIBILITY NOW TO DO SOMETHING

BECAUSE THIS HAS BEEN LIKE THIS FOR 30 PLUS YEARS OF

LEGISLATION IN OUR STATE. SO, WE STARTED OFF WITH WRITING

LEGISLATION. AND I CAN'T TELL YOU TOO MUCH ABOUT THIS

BECAUSE YOU'RE GOING TO HAVE CASE EXAMPLE OF THIS IN A

LITTLE BIT. BUT WE STARTED OFF WITH A PARENTING CASE.

WE HAD A LOT OF PEOPLE WITH DISABILITIES CALLING OUR

ORGANIZATION SAYING THAT THEIR CHILDREN HAVE BEEN TAKEN

AWAY. AND I HAD PERSONAL EXPERIENCE WITH THIS. I ADOPTED --

MY HUSBAND AND I WENT TO GO ADOPT OUR CHILD AND

WE WERE TOLD THAT – SOMEBODY CAME UP TO US AND SAID

I’M SO SORRY BUT YOU'RE NOT GOING TO BE ABLE TO ADOPT

BECAUSE YOU HAVE A PHYSICAL DISABILITY. AND I WAS LIKE

OH, WELL, YOU DON'T KNOW WHO YOU'RE TALKING TO. (LAUGHTER)

SO LONG STORY SHORT. WE ADOPTED. WE GOT HIM WHEN HE WAS

SIX WEEKS OLD AND HE'S EIGHT NOW. I SAW THIS PIECE OF

LEGISLATION JUST IN MY PERSONAL LIFE. SO, IF IT WAS

IMPACTING ME, IMAGINE ALL THE OTHER PEOPLE IT WAS IMPACTING

AND WE KEPT SEEING IT OVER AND OVER.

SO, OUR ORGANIZATION HAS REALLY TAKEN A POSITION

THAT WE ARE CHANGE AGENTS. AND I THINK THAT'S

IMPORTANT FOR ALL CILS TO STEP INTO THAT ROLE AS

LET'S MAKE CHANGE. LET'S MAKE OUR COMMUNITIES BETTER.

BECAUSE NO ONE IS GOING TO DO IT FOR US.

AND SOMETIMES WE DON'T WANT OTHER PEOPLE DOING IT

FOR US ANYWAYS, BECAUSE THEY'RE NOT GOING

TO GET IT RIGHT. SO, LET'S MAKE IT RIGHT IN THE

VERY BEGINNING. SO OVER AND OVER, WHEN I TOOK

ON MY POSITION, I KEPT HEARING YOU CAN'T LOBBY.

YOU CAN'T LOBBY, YOU CAN’T LOBBY. AND I UNDERSTOOD

THAT AND I SAW THAT, YOU KNOW. I CAN'T LOBBY WITH

PART B AND I CAN'T LOBBY WITH PART C

OR ANY OTHER FEDERAL FUNDING, BUT WE CAN LOBBY

WITH UNRESTRICTED AND NONFEDERAL FUNDING.

I THINK THAT'S IMPORTANT FOR CILS TO UNDERSTAND.

BECAUSE WHEN YOUR SYSTEMS ADVOCACY NEEDS TO GO

ANOTHER STEP FURTHER AND CHANGE LEGISLATION,

THEN I THINK IT'S IMPORTANT FOR US TO TAKE THAT

POSITION. WE ALL SIGN A CERTIFICATE REGARDING

OUR LOBBYING --THE ANTI-LOBBYING FORM THAT WE

ALL HAVE TO SIGN EVERY YEAR.

THIS GOES WITH OUR PART C FUNDING, PART B FUNDING

AND THEN ALSO WITH ANY OTHER FEDERAL GRANTS THAT

YOU MAY RECEIVE, AND PROBABLY SOME STATE FUNDING

THAT SOME CILS HAVE, AS WELL. BUT WE SIGN

AND WE CHECK THE BOX THAT WE'RE NOT IMPROPERLY

INFLUENCING ACTIVITIES FOR ANY GRANTS,

CONTRACTS, AGREEMENTS OR LOANS WITHIN THE GOVERNMENT

OR WITHIN OUR STATE. WE ALSO HAVE TO CHECK OFF

THAT WE'RE NOT ATTEMPTING TO IMPROPERLY INFLUENCE

ANY EMPLOYEE OR OFFICER OF THE GOVERNMENT. AND THEN

WE'RE ALSO NOT SUPPOSED TO ATTEMPT TO INFLUENCE

OUTCOMES OF FEDERAL, STATE OR LOCAL ELECTIONS.

AND THAT’S IMPORTANT AND THAT'S SOMETHING THAT

WE DEFINITELY TRY TO STAY AWAY FROM AS MUCH AS

POSSIBLE BECAUSE WE DON'T WANT TO TELL PEOPLE

WHO THEY SHOULD VOTE FOR. AND WE DEFINITELY

DON'T PROVIDE ANY CONTRIBUTIONS OR ENDORSEMENTS

FOR ANYBODY.

WE'RE NOT ALSO SUPPOSED TO CONTRIBUTE – WELL, I

JUST MENTIONED THAT -- ATTEMPTING TO INFLUENCE VOTES

FOR OR AGAINST ANY SPECIFIC LEGISLATION.

THIS IS REALLY HARD -- TO NOT LOBBY IN THIS

SITUATION, BECAUSE THERE'S A LOT OF BILLS THAT

COME UP AND THERE ARE PIECES OF LEGISLATION

THAT COME UP THAT ARE NOT SUPPORTING DISABILITY

RIGHTS AND WILL ACTUALLY DO MORE HARM TO THE

DISABILITY COMMUNITY THAN IT WOULD HELP.

SO, IT IS VERY IMPORTANT FOR US TO SPEAK UP.

WE CAN ALWAYS EDUCATE ABOUT AND USE OUR PERCEPTION

OF HOW THIS BILL WILL INFLUENCE US, BUT WHAT

YOU DON'T WANT TO DO, YOU DON’T WANT TO LOBBY,

YOU DON'T WANT TO GO FOR THAT ASK.

YOU DON’T WANT TO SAY, I ASK YOU TO VOTE NO

OR I ASK YOU TO VOTE YES. IF YOU TALK ABOUT HOW

IT WILL INFLUENCE A POPULATION, THEN YOU'RE

JUST DOING SYSTEMS ADVOCACY AND EDUCATION.

WE'RE ALSO REQUIRED TO KEEP THIS FORM ON FILE.

I DON'T THINK WE EVEN SUBMIT IT ANYMORE. WE DON'T.

WE JUST KEEP IT ON FILE IN THE OFFICE.

WHAT IS ALLOWED WITH FEDERAL FUNDING?

WE CAN PROVIDE TECHNICAL PRESENTATIONS ON TOPICS

DIRECTLY RELATED TO PERFORMANCE OF A GRANT, CONTRACT,

OR OTHER AGREEMENT, IN RESPONSE TO A DOCUMENTED REQUEST.

SO, IF YOU'RE PRESENTING ABOUT YOUR GRANT OUTCOMES

TO FEDERAL OR STATE OFFICIALS. MAKING SURE THAT YOU

HAVE THE INFORMATION IN PRINT AND SO, FACT SHEETS, ANY

KIND OF REPORTS. COSTS OF TRAVEL, LODGING, OR MEALS

FOR ANY TESTIMONY THAT ARE SCHEDULED AND THAT YOU

HAVE RECEIVED A WRITTEN REQUEST FOR.

IF YOU DO NOT HAVE RELATIONSHIPS WITH LEGISLATURES,

YOU'RE NOT GOING TO GET A WRITTEN REQUEST TO TESTIFY.

BUT, IF YOU SEE SOMETHING THAT YOU WOULD LIKE TO

TESTIFY ON FOR A BILL, YOU CAN ALWAYS GO TO THE

SPONSOR AND ASK THEM TO REQUEST YOUR PRESENCE THERE.

AND SOMETIMES THEY'LL DO THAT.

AND THEN YOU ALSO WANT TO MAKE SURE YOU ARE

LOBBYING WITHIN YOUR LIMITS AND YOU'RE NOT

GOING TO HURT YOUR IRS STATUS AS A 501(C)3.

SO, A LITTLE BIT ABOUT OUR LOBBYING SERVICES

OR HOW WE LOBBY.

WE CONTRACT OUT WITH A LOBBYIST BECAUSE THIS

IS A FULL-TIME JOB, ESPECIALLY WITHIN SESSION.

I'M ALWAYS ON CALL WHEN I FEEL LIKE SESSION IS IN.

BECAUSE YOU NEVER KNOW WHEN THESE HEARINGS

ARE GOING TO BE. YOU NEVER KNOW WHEN YOU'RE

GOING TO NEED TO TESTIFY, NEVER KNOW IF

THERE'S GOING TO BE OPPOSITION FOR THE BILL

AND YOU NEED TO GO AND EDUCATE SOME LEGISLATORS.

SO, WE HAVE A LOBBYIST WE WORK WITH. EVERY SINGLE DAY

HE'S OVER AT THE STATEHOUSE SO HE'S MAKING THESE

CONNECTIONS FOR US.

I GO WITH HIM TO TALK WITH LEGISLATORS

ABOUT THE ISSUE. BECAUSE HE IS THE LOBBYIST,

HE'S NOT DOING TO HAVE THE PASSION FOR THE BILL

AS MUCH AS WE DO AND WE CAN SELL IT

TO THE LEGISLATORS.

WE ALSO INVOLVE OUR CONSUMERS IN THIS PROCESS.

MOST RECENTLY WE HAD A YOUTH CONSUMER COME

WITH US TO TESTIFY AND EDUCATE SOME OF THE

LEGISLATORS ON EMPLOYMENT FIRST, WHY EMPLOYMENT

IS SO IMPORTANT FOR PEOPLE WITH DISABILITIES.

NOT ONLY ARE WE TALKING WITH LEGISLATORS AND

CHANGING LAW, BUT WE'RE ALSO CREATING OUR

NEXT GENERATION OF LEADERS.

SHE'S GOING TO PROBABLY RUN OUR CIL EVENTUALLY.

IN OUR ORGANIZATION, WE WRITE THE BILLS.

AND, WE DO THIS IN A NUMBER OF WAYS

BECAUSE WE DON'T WANT ANY OPPOSITION.

WE TRY TO PARTNER WITH ORGANIZATIONS.

SO, ON A PARTICULAR BILL -- THAT PARENTING

BILL THAT WE STARTED WITH, WE WENT TO

PROTECTION ADVOCACY AND WE ALSO WENT TO

OUR DEPARTMENT OF SOCIAL SERVICES.

AND THAT WAS A REALLY INTERESTING MOVE,

BECAUSE THE DEPARTMENT OF SOCIAL SERVICES,

THEY LIKED TAKING AWAY KIDS WHO HAD PARENTS

WITH DISABILITIES. SO, WE REALLY HAD TO

CONVINCE THEM IT WAS A FEDERAL ISSUE

AND IT WAS AGAINST THE LAW.

AND THEN A LOT OF REPORTS THAT CAME OUT

REALLY HELPED US IN SELLING THIS TO THEM.

BUT IT'S REALLY GOOD TO FORM THESE

RELATIONSHIPS BECAUSE THEY WILL ALSO COME

AND HELP TESTIFY DURING ANY HEARINGS

ABOUT YOUR BILL, BUT THEY WILL ALSO NOT OPPOSE IT.

WE ALSO PROVIDE GUIDANCE TO STATE AGENCIES

REGARDING ANY PAST LEGISLATION. AND SO,

I THINK I TOLD YOU EARLIER THAT WE'RE ALSO

MAKING SURE THAT WE'RE INFLUENCING POLICY

WITHIN OUR STATE AGENCIES TO MAKE SURE

THAT THEY'RE FOLLOWING THE LEGISLATION

THAT WE PASSED, BUT ALSO MAKING SURE

THAT OTHER POLICIES ARE ALIGNED WITH

PROTECTING PEOPLE WITH DISABILITIES.

WE ARE REQUIRED TO REPORT TO OUR ETHICS

COMMISSION WITHIN OUR STATE EVERY SIX MONTHS

ON OUR LOBBYING ACTIVITIES.

YOU DEFINITELY WANT TO MAKE SURE YOU LOOK

AT YOUR LOBBYING LAWS AND WHAT IS REQUIRED.

WHAT WE DO IS WE REPORT ON THE AMOUNT OF

FUNDING THAT WE HAVE SPENT ON LOBBYING SERVICES.

AND THEN WE SPREAD IL AND DISABILITY RIGHTS

THROUGHOUT THE SOUTH CAROLINA GENERAL ASSEMBLY.

WHEN WE'RE TESTIFYING. WHEN WE'RE THERE.

WHEN WE'RE PRESENT, WE'RE TALKING TO THEM

ABOUT WHAT'S IMPORTANT. WE'RE FORMING RELATIONSHIPS

WITH THEM, SO THAT THEY COME TO US

WHEN THERE'S ANY DISABILITY ISSUES.

AND THEN WE ALSO REQUEST STATE ALLOCATIONS.

SO THAT'S SOMETHING THAT WE CAN DO NOW, TOO,

WITH A LOBBYIST AND THAT'S REALLY IMPORTANT.

NONE OF OUR LOBBYING IS DONE WITH FEDERAL FUNDS

AND SO, THIS TAKES A LITTLE BIT TO BUILD UP A FUND,

ESPECIALLY IF YOU'RE A SMALLER CIL. IN THE VERY

BEGINNING, YOU HAVE TO BUILD UP SOME

UNRESTRICTED FUNDING TO BE ABLE TO PROVIDE THIS.

AND IT'S NOT FOR EVERY CIL. IT'S NOT FOR EVERY

EXECUTIVE DIRECTOR. IT'S JUST REALLY HOW MUCH

CHANGE YOU WANT TO INFLUENCE IN YOUR STATE.

JUST CAREFUL CONSIDERATIONS WHEN YOU'RE LOBBYING.

CHECK WITH YOUR STATE LAWS REGARDING LOBBYING.

LOOK AT THE NONPROFIT. I WILL GIVE YOU A LINK IN A

SECOND. YOU WILL NEED TO REGISTER AS A LOBBYIST.

I KNOW SOME STATES REQUIRE ANYBODY WHO TALKS WITH

LEGISLATORS TO BE A REGISTERED LOBBYIST.

OUR STATE IS NOT LIKE THAT, BUT WE DO HAVE --

OBVIOUSLY, OUR LEGISLATIVE LIAISON IS A

REGISTERED LOBBYIST.

DOCUMENT -- THIS IS THE MOST IMPORTANT THING

THAT YOU HAVE TO DO. YOU NEED TO DOCUMENT ANY

LOBBYING ACTIVITIES AND YOU NEED TO DOCUMENT IT

IN YOUR DATABASE SYSTEM. YOUR TIME SHEET FOR

THE MILEAGE BEING SPENT AND ANY RECEIPTS, IF

YOU SPENT ANY FUNDING. BECAUSE YOU ALSO WANT TO

MAKE SURE THAT YOU ARE SHOWING THAT YOU'RE NOT

USING ANY FEDERAL FUNDS TOWARDS YOUR LOBBYING ACTIVITY.

SO, WE'RE VERY CAREFUL WITH HOW WE DOCUMENT

LOBBYING ACTIVITIES. BE PREPARED TO SHOW YOUR

LOBBYING ACTIVITIES.

LOBBYING NEEDS TO STAY WITHIN THE PERCENTAGE –

AND THERE’S A LINK AT THE VERY BOTTOM OF THIS

FROM THE IRS. YOU DON'T WANT A SUBSTANTIAL AMOUNT

AND THE IRS WEBSITE WILL ACTUALLY HELP YOU FIGURE

OUT WHAT SUBSTANTIAL MEANS. IT IS SUBSTANTIAL

FOR THEIR REQUIREMENTS. SO, IT IS A LARGE

PERCENTAGE OF YOUR OVERALL BUDGET.

WE SPEND LESS THAN 3 PERCENT ON LOBBYING.

AND SOMETHING WE DO THAT'S REALLY IMPORTANT

IS WE HOST OUR ADVOCACY DAY FOR ACCESS AND

INDEPENDENCE. THIS IS OUR LOGO FOR THE DAY

AND THIS IS A PICTURE IN FRONT OF OUR STATEHOUSE

OF SOME OF OUR ACTIVITIES.

WE ADDRESS THE BARRIERS THAT ARE IMPACTING

PEOPLE WITH DISABILITIES THROUGHOUT OUR STATE.

SO, OUR BARRIERS THIS YEAR HAVE BEEN IDENTIFIED AS ACCESS.

WE HAVE NO ADA COORDINATOR. WE HAVE TWO ADA COORDINATORS

THROUGHOUT OUR STATE AGENCIES AND THAT’S ACTUALLY REQUIRED.

SO, WHEN YOU DON'T HAVE SOMEBODY LOOKING AT DISABILITY

ACCESS OR MAKING SURE POLICIES AND PROCEDURES ARE

IN TUNE, YOU'RE GOING TO HAVE DISCRIMINATION;

YOU'RE GOING TO SEE ISSUES.

SO, SOMETHING THAT WE'RE ADVOCATING FOR IS FOR

OUR STATE GOVERNMENT TO REALLY TAKE THIS SERIOUSLY.

TO START MAKING SURE THAT ADA COORDINATORS ARE

IN THESE STATE AGENCIES. THAT OUR GOVERNOR'S OFFICE

HAS ONE. WE WANT THEM TO HAVE AN ADA COORDINATOR.

THAT'S SOMETHING WE'RE REQUESTING.

WE HAVE TRANSPORTATION BARRIERS GALORE.

OUR PRIORITY RIGHT NOW IS SIDEWALKS.

IF YOU DON'T HAVE SIDEWALKS, YOU'RE PROBABLY NOT

GOING TO GO ANYWHERE ON ANY TRANSPORTATION ROUTE.

SO, WE'RE WORKING ON THAT.

HOUSING IS A HUGE CRISIS WITHIN OUR STATE

AND WE HAVE TONS OF EMPLOYMENT BARRIERS.

WE HAVE ONE OF THE HIGHEST UNEMPLOYMENT RATES

FOR PEOPLE WITH DISABILITIES.

NO ONE ELSE WAS DOING ANYTHING ABOUT IT

SO WE TOOK THAT POSITION AND WE'RE DOING A LOT

ABOUT IT.

BUT THE NEAT THING ABOUT ADVOCACY DAY REAL QUICK IS,

WE DO INVOLVE STAKEHOLDERS.

OTHER DISABILITY ORGANIZATIONS AND OTHER CENTERS

FOR INDEPENDENT LIVING ARE INVOLVED IN THIS PLANNING.

THIS IS A SPIL PRIORITY, SO THIS IS A SPIL ACTIVITY

THAT WE REPORT ON FOR THE STATE PLAN FOR

INDEPENDENT LIVING. BUT OVER 30 STAKEHOLDERS ARE

INVOLVED IN THIS DAY. SO, THEY HELP WITH OUTREACH

AND RECRUITMENT, MAKING SURE PEOPLE ARE HERE.

AND THEY ALSO PROVIDE VOLUNTEER SERVICES

TO MAKE SURE THE EVENT RUNS SMOOTHLY.

BRUCE DARLING: SO WE DECIDED TO FOCUS ON LOBBYING

AND COMMUNITY ORGANIZING/DIRECT ACTION

BECAUSE THESE SEEM TO BE TWO AREAS WHERE

PEOPLE HAVE A LOT OF QUESTIONS IN TERMS OF

SYSTEMS ADVOCACY.

WHEN IT COMES TO COMMUNITY ORGANIZING

AND DIRECT ACTION, IT'S ALL ABOUT POWER.

FREDERICK DOUGLAS SAID, POWER CONCEDES NOTHING

WITHOUT A DEMAND.

AND MALCOLM X ELABORATED, POWER NEVER TAKES

A STEP BACK, EXCEPT IN THE FACE OF MORE POWER.

THERE ARE MANY, MANY DIFFERENT KINDS OF POWER,

BUT FOR US, PEOPLE IS POWER.

UNLESS SOMEONE IN THE ROOM HAS A GIANT PILE

OF MONEY -- RAISE YOUR HAND, LET ME KNOW.

ALL RIGHT. NOT SO MUCH.

BUT IT IS REALLY ABOUT PEOPLE.

COMMUNITY ORGANIZING IS AN ELEMENT

OF INDEPENDENT LIVING. I WANT US TO

THINK ABOUT HOW THIS FITS TOGETHER.

COMMUNITY ORGANIZING AS CONTRASTED

WITH THE SOCIAL WORK/HELPER MODEL

IS COMPLETELY CONSISTENT WITH

THE INDEPENDENT LIVING PHILOSOPHY.

THE LOCUS OF THE PROBLEM IS THE

ENVIRONMENT AND SOCIETY.

THE SOLUTION IS CHANGING THE EXTERNAL,

NOT THE INDIVIDUAL WITH THE DISABILITY.

AND THE SOLUTION IS NOT SECURED BY

PROFESSIONALS, BUT THROUGH SELF-ADVOCACY.

SO, COMMUNITY ORGANIZING AND DIRECT ACTION

REALLY IS SOMETHING THAT CAN BE AT

THE HEART OF A CENTER.

SO, WHEN ADDRESSING AN ISSUE AS A

COMMUNITY ORGANIZER, WE WORK WITH

GROUPS, INSTEAD OF INDIVIDUALS.

HONESTLY, I FIND THAT'S PROBABLY ONE OF THE

MOST EXCITING PARTS OF THAT WORK FOR ME.

DIRECT ACTION. PEOPLE SOMETIMES GET CONFUSED.

THEY THINK DIRECT ACTION. THAT MEANS GETTING ARRESTED.

NO. SO, DIRECT ACTION IS MORE THAN CIVIL DISOBEDIENCE.

GETTING ARRESTED IS ONE THING, BUT THERE ARE

MANY ALL TYPES OF DIRECT ACTION.

DIRECT ACTION INVOLVES A GROUP.

IT IS DIRECTLY INVOLVING THE TARGET.

YOU CAN DELIVER DECLARATIONS BY ORGANIZATIONS,

PETITIONS, LEAFLETS, PICKET, BIRD-DOG,

HAUNT OR TAUNT PUBLIC OFFICIALS (I KIND OF

ENJOY THAT ONE), HOLDING VIGILS, MOCK FUNERALS,

MARCHES, DOING STREET THEATER. WHICH IS AN

EXCELLENT WAY TO ENGAGE QUEER FOLKS, BECAUSE

WE DO REALLY GOOD STREET THEATER.

ALL RIGHT, I’M BEING A LITTLE STEREOTYPICAL,

BUT HEY, IT IS FUN.

HOLDING TEACH-INS, WALK-OUTS, SIT-INS.

OVERLOADING SYSTEMS.

IF THERE IS A SYSTEM THAT'S NOT MEETING

PEOPLE’S NEEDS, THEN OVERLOADING IT.

THAT'S ONE OF THE THINGS WE WERE LOOKING AT

AROUND BUSES -- TYING, UP THE BUS SYSTEM.

BECOMING THIS THING THAT BOLLIXES UP THE SYSTEM.

CENTERS CAN SUPPORT DIRECT ACTION.

SYSTEMS ADVOCACY IS A CORE SERVICE. IT REALLY IS.

FREE SPEECH IS PROTECTED BY THE CONSTITUTION.

IT WAS THE FIRST AMENDMENT FOR A REASON.

WE ALL HAVE THE RIGHT TO FREE SPEECH.

WORKING IN A CENTER DOES NOT MEAN YOU

DON'T HAVE THE RIGHT THE FREE SPEECH.

CENTERS CAN PROVIDE -- EVEN IF YOU HAVE A BOARD

THAT'S A LITTLE TIMID ON THESE THINGS -- CENTERS CAN

PROVIDE IN-KIND SUPPORT (LIKE SPACE TO MEET)

TO GROUPS WITHIN THE DISABILITY COMMUNITY WHO

ENGAGE IN DIRECT ACTION, INCLUDING CIVIL DISOBEDIENCE.

AND CENTERS CAN ESTABLISH POLICIES THAT PROMOTE

OUR MOVEMENT AND PROTECT THE CENTER.

SO, A SPECIFIC THING THAT WE CAN DO.

IF YOU'RE DOING TO DO DIRECT ACTION AND FOLKS

ARE GOING TO GET ARRESTED, TRYING TO EXPLAIN

ON THE TIME SHEET HOW THAT WAS A WORK FUNCTION

IS REALLY COMPLICATED.

WE PROVIDE PEOPLE WITH LEAVE.

AND I KNOW, JUST BEFORE WE'RE GOING TO ALL

GET ARRESTED, BECAUSE ALL THESE LEAVE FORMS

ARE FLYING AROUND THE OFFICE. AND WE ALL

BASICALLY TAKE PAID LEAVE TO PARTICIPATE

IN DISABILITY ACTIVITIES.

IT’S THE SAME FORM WE USE WHEN FOLKS WANT TO GO

TO THE NATIONAL ASSOCIATION FOR THE DEAF CONFERENCE.

THEY’RE ON LEAVE. THEY ARE GOING TO DO THAT

OR GOING TO AN ADAPT ACTION, IT’S THE SAME THING.

BUT HAVING A STRUCTURE TO GIVE PEOPLE THE SPACE

TO DO THAT, SO THEY DON'T HAVE TO TAKE THEIR

VACATION TIME IN ORDER TO PARTICIPATE IN

SOMETHING THAT ADVANCES OUR MOVEMENT,

IT'S SOMETHING CENTERS CAN EASILY DO.

CENTERS SHOULD SUPPORT DIRECT ACTION.

DIRECT ACTION IS TRANSFORMATIVE.

IT SHOWS THAT PEOPLE WHO HAVE NOT SEEN

THEMSELVES AS HAVING POWER, SUDDENLY REALIZE

THEY ARE POWERFUL.

THIS IS AN INCREDIBLY EXCITING EXPERIENCE

TO SHARE WITH PEOPLE. AND EVERYONE CAN DO

SOMETHING TO CONTRIBUTE TO DIRECT ACTION.

REALITY CHECK, NOT EVERYONE CAN RESPOND TO RULES

AND SUBMIT COMMENTARY TO THE FEDERAL GOVERNMENT.

IT'S JUST NOT IN EVERYONE'S -- IT REALLY IS HARD.

BUT EVERYONE CAN PARTICIPATE IN DIRECT ACTION.

THERE'S ALWAYS SOMETHING SOMEONE CAN DO

THAT IS UNIQUE AND CAN BE HELPFUL. THAT'S WHY IT IS

IMPORTANT. IT BOLSTERS OTHER FORMS OF ADVOCACY

WITHIN THE PITCHFORK MODEL.

IT HELPS GET YOU MEDIA.

IT CAN UNDERSCORE SOME OF THE WORK THAT YOU

ARE DOING THROUGH LITIGATION OR LEGISLATION.

YOU CAN SEE HOW ADAPT IS USING DIRECT ACTION

TO ADVANCE THE DISABILITY INTEGRATION ACT.

YOU MOVE PIECES WITH DIRECT ACTION THAT

SUPPORT THE LEGISLATION.

IT WORKS VERY EFFECTIVELY.

THE NURSE'S ASSOCIATION CAN TELL YOU THAT.

THEY HAVE ENDORSED THE DISABILITY INTEGRATION ACT

AND BASICALLY, HAVING NURSES DELEGATE TASKS

TO ATTENDANTS BECAUSE OF DIRECT ACTION.

AND IT'S FUN. IT REALLY IS.

HONESTLY IF YOU HAVE A DARK SIDE, THIS IS HOW

YOU AND LET IT OUT IN A GOOD WAY.

I ONCE TOLD PEOPLE USE YOUR POWERS FOR GOOD,

RATHER THAN EVIL, AND I WAS CORRECTED BY A WOMAN

WITH A COGNITIVE DISABILITY WHO SAID, NO, YOU

MEAN USE MY EVIL POWERS FOR GOOD. GOOD POINT.

GOOD SYSTEMS ADVOCACY RESULTS IN REAL IMPROVEMENT.

IT GIVES PEOPLE A SENSE OF THEIR OWN POWER.

IT ALTERS THE RELATIONSHIP WITH POWER.

AN ADVOCACY ISSUE SHOULD BE WINNABLE.

ONE MIGHT MAKE THE CASE THAT CHANGING THE

INSTITUTIONAL BIAS AND FREEING ALL DISABLED

PEOPLE FROM INSTITUTIONS MIGHT NOT HAVE BEEN

A WINNABLE THING, BUT THE NEXT ONE IS WORTHWHILE.

ALTHOUGH MAY HAVE NOT BEEN AS WINNABLE

IMMEDIATELY, IT IS VERY WORTHWHILE.

SOMETHING SHOULD BE WIDELY FELT.

COMMUNITY INTEGRATION, MAYBE NOT INITIALLY

WIDELY FELT, BUT DEEPLY FELT.

IT SHOULD BE EASY TO UNDERSTAND.

FREE OUR PEOPLE.

OUR HOMES, NOT NURSING HOMES.

WE SHOULD HAVE A CLEAR TARGET AND HAVE

A CLEAR TIME FRAME.

SO, ADAPT’S ORIGINAL DEMAND WAS SHIFT

25 PERCENT OF THE MONEY FROM INSTITUTIONS

INTO THE COMMUNITY.

SOMETHING VERY CONCRETE. DO THAT NOW.

IT SHOULD BE NON-DIVISIVE WITHIN THE GROUP.

THERE ARE PEOPLE WHO DISAGREE, BUT THE GROUP

SHOULD BE SUPPORTING THEM.

IT SHOULD BUILD LEADERSHIP.

DIRECT ACTION DOES TWO THINGS.

THERE'S THE DIRECT-ACTION COMPONENT

THAT TRIES TO MOVE SOMETHING ON THE OUTSIDE,

BUT IT SHOULD ALWAYS BE SOMETHING THE

GROUP ENJOYS, AND IT BUILDS LEADERSHIP

WITHIN THE GROUP.

IT ALSO WORKS REALLY WELL FOR INDEPENDENT

LIVING SKILLS TRAINING. THINK ABOUT THE KINDS

OF SKILLS YOU USE WHEN YOU DO DIRECT ACTION.

THAT'S HOW OUR CENTER BRINGS SO MANY PEOPLE

INTO THE PROCESS.

IT LAYS THE GROUNDWORK FOR THE NEXT CAMPAIGN

AND SHOULD BE CONSISTENT WITH YOUR VALUES.

AND THIS IS ALL FROM ORGANIZING FOR SOCIAL CHANGE.

SOME OTHER TIPS TO REMEMBER.

ANYONE CAN BE A LEADER.

SO, IT IS REALLY ABOUT – AND I WANT YOU -- WHEN

YOU GO BACK AND YOU'RE LOOKING AT YOUR CENTER, THINK

ABOUT WHO COULD HELP BUILD A DIRECT-ACTION RESPONSE.

IN RESPONSE TO THE PROPOSED CUTS TO MEDICAID

AND THE BLOCK GRANTING OF MEDICAID,

CENTERS ACROSS THE COUNTRY MOBILIZED.

JUST SO YOU KNOW, ALTHOUGH YOU SAW ADAPT ACTIONS

HAPPENING OVER THE COUNTRY, MANY OF THOSE

ADAPT ACTIONS WERE POP-UP ACTIONS ORGANIZED

BY CENTERS WHO CARRIED THE BANNER ADAPT.

THEY DID IT RESPECTFULLY AND ACTUALLY HONORED

THE NAME AND CARRIED THAT MESSAGE.

WE HAD ACTIONS FROM FAIRBANKS ALASKA DOWN TO

HERE IN PHOENIX OVER TO ORLANDO, FLORIDA

AND UP TO PORTLAND, MAINE AND A WHOLE LOT

OF PLACES IN BETWEEN INCLUDING CHICAGO

AND INDIANAPOLIS. THERE WERE ACTIONS EVERYWHERE.

THOSE PRIMARILY WERE ORGANIZED THROUGH CHAPTERS

AND CENTERS. WE DID THAT AS A COMMUNITY,

SO WE CAN OWN IT AS A STRENGTH.

INVEST IN PEOPLE BY USING THEIR STRENGTHS.

THE MOST IMPORTANT VICTORY ISN'T – AND THIS

IS IMPORTANT – THE MOST IMPORTANT VICTORY ISN’T

WHETHER YOU PUT LIFTS ON BUSES OR NOT,

IT'S THE GROUP. GETTING PEOPLE TOGETHER

AND MOBILIZED AND HAVING REGULAR MEETINGS

AND ENGAGING IN ADVOCACY IS THE VICTORY.

I LIKE TO TELL PEOPLE, LEVERAGE OUR PERCEIVED

WEAKNESSES AS STRENGTHS.

IT'S SOMETHING THAT I THINK IS REALLY

RELEVANT WITHIN THE DISABILITY COMMUNITY.

WE HAVE A WOMAN IN OUR CHAPTER. HER NAME

IS SHELLY. SHE HAS A SPEECH IMPAIRMENT.

SHE'S VERY ENGAGING, BUT IT TAKES A LONG TIME

TO TALK WITH HER AND YOU HAVE TO PAY CLOSE

ATTENTION. SHE NOW NEGOTIATES WITH THE COPS

AT ALL OF OUR LOCAL ACTIONS.

WHY IS THAT? BECAUSE IT TAKES A LONG TIME

TO FIGURE OUT WHAT’S GOING ON.

AND BY THE TIME THEY HAVE FINISHED THE

CONVERSATION, THEY HAVE BEEN PERSONALLY

ENGAGED WITH HER, THEY'RE INVESTED IN THE

RELATIONSHIP WITH HER. IT HAS REALLY MESSED

WITH THEIR MINDS. THEY'RE NOW ON OUR TEAM.

THEY JUST DON'T REALIZE IT.

AND ONLY SHE COULD DO THIS. THIS IS SOMETHING

SHE BRINGS UNIQUELY TO THE GROUP.

SO, LOOK AT OURSELVES, PEOPLE DO SEE OUR DISABILITY

AS A WEAKNESS. IT’S A PERCEIVED WEAKNESS.

TURN IT INTO A STRENGTH.

AND NEVER DOUBT -- THIS IS MARGARET MEADE—

THAT A SMALL GROUP OF THOUGHTFUL, COMMITTED

CITIZENS CAN CHANGE THE WORLD.

INDEED, IT IS THE ONLY THING THAT EVER HAS.

I THINK THE SUMMER OF ADAPT, WHICH WAS DONE

IN CONCERT WITH CENTERS FOR INDEPENDENT LIVING

ACROSS THE COUNTRY DEMONSTRATED THAT.

THE COUNTRY WAS POISED TO DESTROY MEDICAID

AS WE KNOW IT. THEY WERE POISED TO ELIMINATE

THE AFFORDABLE CARE ACT AND WE STOPPED THEM.

AUDIENCE: WHOOHOO! (APPLAUSE)

BRUCE: YES. THERE IS A LOT OF POWER IN OUR

COMMUNITY, IN OUR NETWORK. IT'S ABOUT HOW WE

LEVERAGE IT AND USE IT.