

CADRE Webinar
Moving Beyond Disputes:
Mobilizing and Orchestrating a Village when Extensive Change is Required
Ann Turnbull
January 21 2016
Transcript

Well hello and thank you for joining the CADRE's webinar with Dr. Ann Turnbull. Today's webinar is Moving Beyond Disputes: Mobilizing and Orchestrating a Village when Extensive Change is Required. Today's webinar is one in a continuing series of CADRE webinars. You should hopefully be seeing some poll questions on your screen now, please take a minute to answer these. A few technical notes. Phone lines have been muted to minimize interruption. When we open up the call for questions later on, at the end of Dr. Turnbull's presentation, you press pound six to unmute your phone, and then star six to re-mute. We do recommend calling in using a telephone rather than computer audio. You can also enter any questions or comments in the chat box in the bottom right-hand corner of your screen. CADRE staff will be attending to those throughout the webinar. We'd like to also note that the PowerPoint and handout for this webinar are available at the link on your screen, or scroll to the bottom, and scroll to the bottom of that page and you'll also find these materials in the file pod located above the chat box. We especially recommend downloading the handout now if you are able to do that. Now we do have a couple of new technical aspects, a couple of new technical aspects to this webinar. This is the first webinar that we're hoping to live caption so, and we're hoping that will occur, and we'll also, for the first time ever, be showing a number of videos during the webinar, so please bear with us and let's hope that the technology gremlins stay in hiding today.

So for four decades today's presenter, Dr. Ann Turnbull, has been a professor, researcher, who advocates for individuals with disabilities, for families and service providers. She's authored 32 books and over 250 articles and chapters. In 1999, she was selected as one of 36 individuals who have changed the course of history for individuals with intellectual and developmental disabilities in the 20th century. Ann's greatest learning has come from her son Jay Turnbull, she has always called her best professor. On April 2nd of last year, Ann presented a very well-received CADRE webinar entitled Trusting Family Professional Partnerships: Preventing, Resolving and Moving Beyond Disputes. And you can find a recording of that and all of the CADRE webinars on our website. It is our very good fortune to have her pay us a return visit. Now I turn it over to Dr. Ann Turnbull.

>> Thank you so much Phil and thank you Noella, both of you have been wonderful partners to work with on this. And hello everyone, I am very happy to have a chance to share with you, and I want to do a special shout out to you Leslie Gerard in Kansas. I lived in Kansas everyone for 34 years and my husband and I moved to North Carolina for retirement a year ago and Leslie was definitely my reliable ally for many years and always will be. So welcome Leslie and welcome everyone. And let's jump in because there's lots that I want to share with you and this opportunity to think about how we approach the extensive change that is often needed before, during and after disputes, and how we get the help and partnership of others to do just that. Well, look at this slide and let me ask you, have you ever felt like this donkey? Now I have felt like that donkey before in having just too heavy of a load to pull and,

you know, sometimes what's just so ironic and unfair is that when we have great visions for the life that people with disabilities can have, the load seems even heavier, because so many services and so many supports have to change often for really wonderful visions to happen. This is exactly how my husband Rud and I felt, many years ago now, it was actually in the late 80s, early 90s, and it was the time that our son Jay was transitioning from high school to then, and still in so many places, sheltered workshop, group home, segregated living as an adult, and our vision was inclusive adult living, and oh that load, that vision, made everything that needed to be done so extensive.

>> If you can hear me, we can't see the slides.

>> We can't see anything.

>> [INAUDIBLE] we can't see them.

>> Well thank you for letting us know that. Now Noella and Phil I'll ask for your help with this.

>> Yeah it might be something on their end. Please send us a chat, go ahead and continue Ann.

>> Okay. So, the next slide, and I will describe it, it's a table of the typical IEP transition planning meeting with people sitting around and two people fighting in the middle, and that fight, that dispute is something that many of us have encountered, and it often occurs again because these visions require change and change is, often it's easier to say that is unrealistic, that can't really be done, what you're asking is too much, rather than to embrace the complexity of change. So, moving on, just think about change over the lifespan. Most of my comments are going to be about our family experience that focused on the transition between adolescence and early adulthood and in creating an inclusive adult life, but the process that I'm going to be talking about, group action planning, can occur at every lifespan stage. In fact, my most successful observation of this has been a family in Lawrence, Kansas, the Schaffer family, who started doing group action planning during their daughter's early intervention program, and have continued to do that across the lifespan. This is a young girl with Down Syndrome who, at every stage, the family was pushing for full inclusion, and every stage it took extensive change, and now Sarah is in the third year of college at Washington University in Topeka. They really have done a phenomenal job and it's because they learned to orchestrate a village.

So, our next slide here is of Sisyphus from Greek mythology pushing that heavy, heavy rock up the hill, and this is how Rud and I felt after we had had a dispute with the school and they were unwilling, at that time, to create options for inclusive adulthood, saying that we were being unrealistic and that Jay was far too significantly disabled to have an inclusive adult life. So we tried to think, how can we do this on our own, but what we learned, with this next slide of a whole group of, and we see here animals, but a whole group working as reliable allies together to make that change possible. And, you know, I was out in mountains of North Carolina this past weekend talking with a friend who had recently been to Africa on a safari, and she was saying that she learned on the safari that the zebras and giraffes and antelope often hang together because one of the group, one of those groups has excellent seeing, another excellent hearing, and another excellent smell, and they know, when they work together, they can best preserve their safety. I thought that's the essence of what I want to share, is when we pull together

reliable allies, and everyone has a different talent and everyone has different strengths, then we have so much more power to create the change that is needed.

So, I love this quote, and this is going to be a theme of our conversation with each other today, 'The law of accumulation, that the sum total of a lot of little things isn't little.' When Rud and I realized how much needed to change for Jay to have a job, and for him to have a home of his own, and for him to be able to use public transportation and for him to have friends around the community, and for him to have the behavioral support that would keep him safe from having aggressive outbursts, then we really realized that it wasn't going to be one or two or three huge changes that happened immediately, but we were going to have to work over time, with a lot of little change, that would add up to a lifestyle for him. So at the beginning let me give you the take-home messages of this webinar, that you can best achieve extensive change through many little collaborative acts, rather than a few monumental acts. You need a village of reliable allies to carry out those collaborative acts on a weekly basis. Extensive change doesn't happen quickly, and it doesn't happen really episodically, but it happens when there's systematic work week in and week out. Engage every week in little collaborative acts aligned with your great expectations or visions. By doing so, quality of life will accumulate, and group action planning, that I'm going to focus on today, is a structure for getting a synergistic reliable alliance, with family, friends and community citizens, to make change over the lifespan. So that is the main focus.

Now I want all of you to think about an extensive dispute, I mean a dispute that has needed to have extensive change around which you have participated. That might be you participated as a family member, you participated as a professional, but think of a situation where a lot needed to change, and as we go through group action planning, keep thinking about how this process might work for you. There are five what I call stages, or phases, of group action planning and we're going to talk about each one of those, and we're going to start with the inviting support and, you know, so often, as family members or as professionals also, we think, gosh if we have to ask other people for help that's a sign of weakness. But what I want to really emphasize is asking others for help, and to be part of the team to make extensive change happen, can be a sign of strength, and that there are tips and there are solid practices, and I like to use the phrase inviting support rather than asking for help. For you to think about how can you invite others to help with this big, big job that needs to be done involving the extensive change. Well, at the beginning Phil had encouraged you to print your handout, and the handout for this session is aligned with each of the tips that I'm going to talk about for each of the five phases, and we'll start here with tips. So here, if you look at number five here, consider great expectations, if you go to your handout, number five is about great expectations but it's in more depth and more information is provided. Now if you didn't have the chance to print your handout that's fine, you can do that later, but the handout will be able to go into more depth than I'm able to do in an hour and 15 minutes that we have together, so I really want to call your attention to that as a very practical guide for you taking what I'm suggesting and implementing it with your own need for extensive change. But in thinking about inviting support, a very key thing is to, well let me back up before I get to the facilitator, the idea in group action planning is that you might have six or eight or ten people who you pull together on a regular basis, and that is your problem-solving team, those are your reliable allies. Now a lot of you may have had training and had experience with what is called person-centered planning or the maps process, and what often happens in those kinds of arrangements, let's say a typical implementation or person-centered planning, is that people get together yearly, annually, and they come up with great ideas for

what might improve the life of someone, but then they don't come back together for another year, so at the end of the great ideas, then it's just the family, or it's just the professionals that implement those, it feels like too heavy of a rock to push up the hill, and often people give up. But, when you have, bring together a group, and you meet on a monthly basis, and during that month, between meetings, every member of the group is working on maybe one task, not more than two tasks that need to be done, then you can accumulate all of those little changes that add up to the lifestyle change. But with this group you need to think about who's going to facilitate it, and the facilitator needs to be a person who can be systematic in getting people's attention and moving the conversation forward and going through the steps of problem-solving, so you need a person who has some structure and some organization, but you also need a person who's fun, and who can inject warmth and laughter into the process. In fact, when Rud and I were first trying to figure out this group action planning, when Jay I'll say, was expelled from the segregated program in our community just several months after he entered it because he was so unhappy there that he started acting out and engaging in aggressive behavior of hitting and choking and pulling hair of others and, you can imagine, he didn't last long, so here Rud and I were needing to figure out how we were going to create all of this change, of a home and a job and transportation and friends, on our own. So a key thing is finding a person to facilitate, in our situation I was the facilitator but I don't recommend that, I think it's better for the focus family to not be the facilitator, but I was the facilitator because we just weren't sure what we were doing and we were just trying, trial and error. I had facilitated a number of other groups for people, and I have found it to be a very enjoyable process to be a facilitator for people who are trying to make their dreams come true. So maybe from the parent training information centers this might be a project of some of the staff being facilitators and also training other facilitators so, you can read more about the facilitator on the handout but remember that organization and balance.

Then who were the people? In Jay's case, when we, you know, knew he needed change, the people in his group started off being Rud and I, his sisters, when they were available to come, some of his friends from our church, some of the professionals such as the person at the University of Kansas, Jane Wagner, who is in charge of the speech and language clinic, and because Jay loves music more than anything, then we thought well gosh, who is a person who can help bring music into Jay's life, and we thought well let's ask Alice Ann Darrow, who was a music therapy faculty member at the University of Kansas, who had access to students every semester who loved to do music with people with disabilities. So, as you think about who to invite, you think about people who can open doors, you can think about people who are, have an emotional connection such as Jay's sisters, or friends from our church, and as Jay started getting more and more of a life, as he started, as he was able to get a job, also at the University of Kansas, through one of the members of the group, then, coworkers, who were the coworkers who seem most committed to him, and then we would invite them to join the group. So, you can go to your handout for more detail but just to give you that big overview, and one more thing I want to add, number seven here, issue personal invitations. And we found that, in a group I was facilitating for a young man with an intellectual disability who was in middle school and who was wanting a more inclusive life, I went to his church and talked with the Director of Christian Education and asked who were a couple of the leaders in the Sunday school class who we might tap to be part of Lyon's group. And I called one of those young men and asked him to join and he said he would be glad to do it and he was part of the group for about the next seven years before he went off to college, but when I ask him, why did you agree to this, I was asking him several years later, he said because you personally called me.

You know, you didn't just come to Sunday school and say would anybody volunteer, but you called me, and you asked me by name to do this, and I felt an obligation. So, that was really a lesson about giving personal invitations.

Well let's move onto creating connections, and I'm going to show you a couple of videos of one of Jay's meetings, and then I want to talk about the kind of ambience that we try to infuse into group action planning. So as you watch this video, be thinking of how similar and different this is to an IEP meeting, okay. So.

>> Jesus Rosales. I used to live with J.T. for one year and a half, and we became really good friends.

>> What song do you sing with him, Jay?

>> Jesus

>> What do you sing with him?

>> No no no, señor [song in Spanish] (laughter)

>> You know, that's a song in Spanish, that is, "No no no no, Señor, [SPANISH LANGUAGE]."

>> That's when Jay became bilingual. (laughter)

>> You're doing more than your parents.

>> Jesus and Shala got a new apartment.

>> That's right. Jesus and Shala do have a new apartment, but you go over to see them, and they come over to see you, which is great. Right?

>> Yeah.

>> Okay.

>> Okay.

>> I'm Cory Royer, I've known Jay five or six years, was his roommate for a long time. We were in the same fraternity together. We used to hang out and do a lot of things together.

>> Washing hair.

>> Well, we do that too, buddy. That's right. We wash our hair really good now. And I also taught him a language, but that's – yeah

>> It takes Jay a little bit longer to wash his hair than Cory, huh? I'll bet it gets -- Cory needs to learn how to shave, don't you think, Jay?

>> Yeah, I do.

>> He's got the beard, that's terrific.

>> Cory, what's your language?

>> What's the language?

>> [Cory and Jay make funny sounds]

>> Oh, well. (laughter)

>> But it's just --

>> Put me on the spot there, buddy!

>> Cory, why don't you explain that to everybody.

>> Well, somehow it just came about that Jay and I used this little language -- [Cory makes funny sounds]. Thank you. (laughter) Oh, but anyhow, we have our own little way of talking on occasion. And he does that and gets me going, then I do that and get him going. But I always look a little silly.

>> Only men understand it. The male roommates.

>> It's a male bonding thing to do.

>> It truly is.

>> And Tom has got it down very well. (laughter) Oh, J.T.!

>> One of the great things about Cory's language ability there is that it was an instant connection with J.T. And then we wondered who's shaping who's behavior...

>> He is.

>> Okay friends, I hope you just feel the sense of connection. Now let me tell you, this group, we had been meeting together as a group for about three years when this tape was taken. By this time Jay had gotten a job at the University of Kansas, he had gotten taken into a fraternity, Corey said he was Jay's fraternity brother, we never in a million years thought Jay would be in a fraternity, and then the fraternity brothers, Corey and one other guy, asked us if, or told us they thought Jay should move out into his own home, and we, you know, thought how in the world are we going to make that happen,

that rock seemed so heavy to push up the hill, and they said we want to be his roommates. Now never in a million years did we think people without disabilities would come to us saying they wanted to be Jay's roommate, but that had happened because Jay had been taken in as a, to this fraternity, and the guys bonded with him. Now you might think well that's, you know, that's only going to happen once in a million years, but I'm so happy to say that the guy who was most instrumental in that, started an organization at the University of Kansas, Natural Ties, that's lasted over 20 years, where now about a hundred people with disabilities are brought into campus organizations, and form a close emotional bond. So, that's just a little bit of that background. The meeting that we were having this night was a meeting where we were really focusing on, okay, now that Jay has a job and has roommates and a home and things are, you know, beginning to really fill out in his life, what would happen if Rud and I kind of went down in a plane together? Or, you know, the worst fear that so many parents have, especially ones with great visions for inclusiveness, is what would happen if they're no longer able to facilitate that? And so that's why we were meeting. And this next little video that we're going to see, let me give you just a background, Jay got a new job coach the day that this meeting was that evening, and so his new job coach was at the meeting and, as facilitator, I asked everyone to go around and to say one positive thing about Jay, one thing that they really valued, and as you listened to this, think this was the young man who was kicked out of the only adult program in Lawrence because they felt he was too disabled to be in a sheltered workshop, and too disabled to be in a group home, listen to, when you flip from what are his deficits, to what are his strengths, listen to what people are saying about him, letting the job coach know what a neat person he is.

>> He only has nice things to say about people, and he has no enemies, a lot of good friends.

>> Good.

>> Well, Jay has a really good heart, and he means well to all the people.

>> I think Jay really knows how to enjoy life. And I've learned how to enjoy life just by being around him, slowing down, he knows what he likes, and he won't be pushed.

>> That's right.

[laughter]

>> Well working with him today I found out he's a hard worker.

>> Good.

>> Worked just right along, everything I asked, he just took it and did it, so it's great.

>> And I did it on my phone.

>> He always sings song with me. Whenever I want to sing a song, he always sings.

>> Good. Rud?

>> He's my best buddy.

>> Best buddy.

>> He's my best buddy.

>> Great.

>> Best man.

>> You're my best man JT.

>> That's me.

>> He's very empathetic with other people's feelings, particularly their sadness or their frustration, that he really likes to comfort and nurture others.

>> Good.

>> He's very simple, and he appreciates things that are very simple.

>> Good.

>> And I'll add to that that he's quiet, you don't feel, with Jay you don't feel obligated to entertain, it's just, let's be together.

>> Okay.

>> There's a formal course that's taught in a lot of colleges and universities and it's called Music Appreciation, and Jay would be a great person to teach such a course because he is the greatest appreciator of music.

>> Good. I'd say lots of friends.

>> That's right.

>> Lots of friends.

>> He knows what he wants and he's not afraid to tell you. [laughter] Ever.

>> Jane?

>> He's very caring and he's very cheerful, he always greets me every day, comes down the hall and says hello and I appreciate that.

>> Yeah.

>> I like to talk to Jay.

>> Dela?

>> Jay's very rhythmic. He has more rhythm than so many people that I know and he's very, very musical music is very important to him.

>> Jay, how about yourself? One positive comment about yourself?

>> Yeah.

>> Something happy about yourself?

>> Smile.

>> You smile? You smile a lot, yeah. That's good.

>> Yeah.

[silence]

>> All right, well I hope that you felt, as you saw this, some of the suggestions and the tips about creating connections, that as you look at, on the slide, that nine through 14, think about the sense of connectedness, the informal socialization, the infusion of laughter and avoidance of somberness, and that is, what one person said who was coming is that he couldn't decide if he was coming to a meeting or a party. And you know we all go to so many meetings and so many drain us, and we leave depleted, and our goal was to create the kind of gathering so that people would feel uplifted, and because, when people feel uplifted, they are more willing to be part of the solution, they're more willing to help push that rock up the hill, because they have energy. And this turning a crisis into an opportunity, there were times when Jay would, not very often, once he was in an inclusive lifestyle, but at times of high stress for him, he might pull someone's hair at work or, when he was on campus, coming to his job, he might do something that was very inappropriate. And what we found, those crisis times were times that people would bond together to try to overcome the crisis, so rather than keeping the crisis a secret, or rather than trying just to resolve it ourselves, once we opened up with everybody, that Jay pulled a coworker's hair and it was an awful situation at work, then we really come together and work on what needs to change so that that will not happen anymore in the future. So, the creating connections.

Now the third part of the group action planning is sharing great expectations, and for so long when, before group action planning, when we would try to share great expectations with the high school staff

that was responsible for transition, they would tell us we were unrealistic, or they would say that we just would not accept the extent of Jay's disability and we were pushing him too far. And, you know, what was so wonderful for us and the action group is that often other people's expectations were ahead of ours. So instead of us being the one out front saying what do you think of this idea, I remember one of Jay's roommates was suggesting that Jay should learn to ride, to use a taxi, and then, after he learned to use a taxi, he should learn to use the city bus. And I just didn't know if that would be possible, given the fact that Jay might have a behavioral problem, you know, an aggressive incident that could get him arrested, or someone might steal his money or someone might bully him, I mean you can come up with all sorts of problems, but the great thing was that Rud and I weren't the people who had to figure that out by ourselves, but everybody in the group kind of thought, how can we work together, and what kind of step-by-step process can we take, to move in the direction of Jay not needing his roommates, or not needing his family, to transport him. So, the synergy of a lot of people who were creative was so wonderful in pushing limits.

Now our next slide, and I think, oh, first there are tips on your handout about how to kind of facilitate and affirm and the guidance of staying open to new ideas. So we move into solving problems, and I think we'll not see this video because of our time, but I can tell you about it. The key part of group action planning is solving a problem. You know at first it was the problem of employment, then it was the problem of where was Jay going to live, where are we going to get housemates, then it was the problem of transportation, then it, you know, might be some crisis thrown in there with behavioral problems that would occur or, you know, just, roommates leaving and needing to recruit someone else, job coach leaving, needing to recruit someone else, so there were always changes, and always issues that needed to be addressed, and as I told you, at this meeting where I'm showing you the videos, we had kind of pulled back from any particular thing that needed to change in Jay's life immediately, to think about how can we set this up so that it's not so dependent on Rud and I making sure that everything could work out. So we had the whole group, you know, think with us, about what would happen if Rud and I were not able to do it. Now, think about our daughters. Our daughters at this point were, as I remember, about 15 and 18. And, you know what's often not addressed in families is what the siblings' role is going to be, but it was so powerful for our daughters to be there, and to know how many people cared about Jay, and know that if something unthinkable did happen in our family, they were not going to be the Lone Ranger, and that was really important. Our older daughter Amy said that night, she said, well I hope I'm at least 35 before my parents die, and now she's 40, and is so glad that we're still living. But for her, at that age, at 18, 35 seemed so old, but as we all know, 35 is not that old. So the key issue, and the facilitator's role is to ask for options, you know, what, how could we make this work, to look at the pros and cons of options, and to develop an action plan, and what we tried to do with that action plan is at every meeting, to think about what are the tasks that need to be done in order to address the problem that we are addressing, and then thinking if everybody here could do one task, you know, if there are ten people at the meeting and everybody does one task, then ten tasks get done before the next meeting. And the only paperwork that we had is that we would. I would send out a one page email to people with a bulleted list of what each person's task was. And then we would start the next meeting reviewing that list, and what everybody knew, if they just had one task, it seemed manageable. If they just had one task they didn't have to drop out of the group because it was too overwhelming. If they just had one task they wanted to be able to report it at the next meeting. So there was a strong sense of manageability and accountability, and that we were all working together to

push the limits of what could happen for this wonderful young man who deserved a good life. So, on your handouts, you will see a number of tips that basically go through the steps of problem solving, and guide people into coming up with a good action plan for the one or two issues that you're addressing at each meeting. Remember, one step at a time makes it possible.

So, our last phase of group action planning that we love, that we tried to do regularly.

>> Ann?

>> Yes.

>> Here's a question that I think is somewhat timely, and somebody

>> Yeah.

>> Has asked if Jay also was assigned some tasks.

>> That's a very good question, and it depended upon what the tasks were. But given the extent of Jay's disability, he experienced a very significant intellectual disability, autism and a bipolar disorder, and, for example, with the bipolar disorder, if he was in a highly depressed mood and phase of his cycle, then that would not be a good time, in some instances, for him to take on a task. But if he wasn't in a particularly high or low cycle, and it was a task that was manageable for him, and also, sometimes he would be doing a task in conjunction with a roommate, or in conjunction with his job coach, so that it wasn't a single task but a shared task. And, but group action planning can be done with people with average and gifted intelligence and, in fact, when my father was in his 80s and had some major health setbacks, and he moved from Georgia to Kansas so that Rud and I could be care providers for him, we did group action planning with him as well, you know, and he was at a very different position than Jay in terms of being able to participate more and to take more responsibility. So it all depends upon the capacity and the support that's provided to the person, that's an excellent question, thank you.

Okay, moving on to celebrating success. We tried to do that in lots of different ways as you'll see on the handout, and not just celebrating the success of Jay's life but celebrating the birthdays of people in the group, and celebrating holidays together and doing the sorts of things that would bring us into closer connection. But I especially want to show you the celebration of success at this meeting, which was talking about the scariest thing in our life, which would be an untimely death of Rud and me, and what would happen. So, at the end of the meeting, where you've seen some of the segments, this is the celebration that we did. One of the great things, I think if we all open our candles, is that, that every candle that people have is a different color. If you kind of look around the room they're all the same size but they're all a different color, and every candle is a different fragrance. And we should light our candles. If Rud and I were the only support for Jay there's just this much light that could generate for his life, and as hard as we worked or as much as we tried to do, it would still be just the one family light. We kind of go to sisters and they add to his life and each of you here add. You look at all the light, and as Rud said earlier, I think one thing that we learned when they said to us, what are you going to do when you fail, is that it was going to be better for us to light a candle than to curse the darkness. But it's

really all of the light from all of our candles that make this possible, and Rud was saying earlier and we want to underscore it so much, that the lights that shine here for Jay shine for each of you, and that, as we look around the room, I really hope that we all have a sense that one of the greatest things that people with disabilities need is to have people to belong to, but it's one of the greatest needs that we all have. And through coming together for Jay we come together for each other.

>> Well can I say something and you'll be happy for the day?

>> Uh-huh.

>> I mean you have honored me with great compliments and with great help and I always have the sense that you, that I feel that when you talk, that you owe it to me and that I'm giving you a great favor, and I have never expressed back and I think that is, I'm sure that if we ask here around the room they probably would share the same feelings, and what I want to say is that I would like to thank you for giving us the opportunity to interact with Jay, not because he's so great and he's so amicable and likeable and such a good friend, but because what I think that you're doing, it is really unique. And you are pushing the frontiers of mental retardation into being, not so much an exclusive disability, but more like an inclusive disability that everybody has to share. I would like to thank you for giving me the opportunity to be part of this enterprise.

>> [singing] I'm gonna let it shine, let it shine, let it shine.

>> Five years ago we couldn't have thought of tonight, and the exciting thing for all of us is with all of the different gifts and talents represented by all the different colors of the candles, what will the year 2000 be like in Jay's life? What will 2010 be like? What will 2020 be like.

>> We won't fit in this room that's for sure.

[laughter]

>> [singing] This little light of mine, I'm gonna let it shine, this little light of mine, I'm gonna let it shine.

>> And for everything that you've done for all of us, we thank you. And for everything that we all have to look forward to in the future, we celebrate. Thank you very much.

[singing] Let it shine, let it shine.

>> All right.

>> Yeah.

>> That was great.

[silence]

>> Okay friends, I want to emphasize several things. Jesus, who had been one of Jay's roommates, said thank you for giving me the opportunity to be part of this, and that's what I really want to emphasize because so often we think it's weakness to bring in other people, but what Jesus is saying is how much he appreciated it, and that's because would he have appreciated it if we had run group action planning like the typical IEP meeting? No. He appreciated it because the support for him was there when he was a roommate, all of those people were going to help him be successful as a roommate, he wasn't the Lone Ranger himself. And that we, by strengthening the emotional bonds, then people get so much reciprocity out of what they are investing. I also want to say, I made some comment there when they said what are you going to do when you fail. And to give you the background to that, when Jay was being expelled from the adult agency in town and they were meeting with us to tell us that, Rud and I were saying that our vision was, you know, that Jay would have a real job and a real home, and real friends and a real wife, and the director of the program said, what are you going to do when you fail? And what he was really saying is we, he knew Jay was far too disabled to have any of that, and that he knew probably sometime we were going to be coming back begging to get back into the program. What are you going to do when you fail? And that, you know, was such a powerful motivator for us to not fail. And then I want to point out, I don't know if you heard it, when I was saying what's the year 2010 going to be like, 2020, and Amy McCard, our friend who was a behavioral specialist, who helped us a lot with behavioral challenges and was supporting Jay during his depressive cycles, Amy said, we won't fit into this room. And I want to come back to that.

Now somebody has asked a wonderful question. Were we fearful of Jay's safety because so many people were involved with him, and how did we overcome our fear? You know what we learned? We learned that the greatest social security, it's not the money of social security, the greatest social security for Jay was caring relationships. When the people in this group cared so deeply about Jay, and Jay cared so deeply about them, no, we didn't worry. You know when we learned to worry, and I'm sorry to say this and I wish our experience had been better, our greatest worry had come from Jay being in a segregated disability system that did not treat people with dignity. Now, like for example, when he was in the group home and when he didn't want to get up in the morning, and resisted getting up, then the staff members started, got a water gun and would shoot water in his face. And that's what we worried about, that often parents think, and professionals think, that the greatest security is disability agencies. You know it used to be institutions, now it's group homes and sheltered workshops but they're segregated programs and communities. What we learned was sharing relationships are what give people safety and security, and I would be happy if, to come back on with any of you, and to give you example after example of amazing, caring, loving, thoughtful support that came from ordinary citizens in the community. It blew us away. That if Jay had been going around on a little bus with six or eight other people with disabilities and they were all walking together in a group, sometimes I use the word herd, in a herd, people wouldn't have gotten to know Jay. That's what segregates, is when people with disabilities are so congregated that you can't really know them as individuals. Jay's greatest safety came from being part of the inclusive world, and not being part of a larger group of people with disabilities that enable people to truly get to know him as a person. And this question Janice, that came from you, oh I would love to get into that, how have our daughters grown through this experience? One of our daughters, Kate, who is 37, and I are now doing sibling presentations where, you know, Kate and Amy have taught us so much about some of the things we missed, and the main thing we missed was the fear

that they had about Jay's aggressive behavior, that, you know, that's been a tough issue for them to deal with over the years. But those girls, now women, have learned to be advocates, they learned to put their heart out for other people, and it has so shaped them, one of them works in mixed income housing in Chicago, supporting people who experience poverty to have decent housing, and the other is now going back to school, after being an actor, to be a counselor, where she especially wants to work with people who experience poverty and people with disabilities, and people of color, in terms of how to really have the quality of life that they deserve. Jay was such a profound teacher to his sisters. But there's some good, some bad and some ugly that were part of that, but what the girls talk about from this meeting, this group action planning meeting, is how wonderful it was for them to know that if something happened to their parents, that there were so many people who cared.

Well, what you're going to see on your handout is tips for celebrating success, and that celebration was so critically important to keeping people energized, so that we could travel this road together. Now remember how we started, 'The law of accumulation: the sum total of a lot of little things isn't little.' Think about meeting together for three years, meeting monthly, having a different problem to solve at every meeting, having eight or ten or 12 people all with one task to do, think about all of the little things that got done without wearing any of us out. So, here are your take-home messages again, I will not read through them, you have access to this handout, but you know that it does take a village, and extensive change is hard, and after disputes, when there's an adversarial element, you know, it's hard to kind of overcome that, and what Rud and I learned is reach out to ordinary people, give them personal invitations, think about people who can open doors, like Alice Ann Darrow the music therapist, who, every semester for the rest of Jay's days, he had a music therapy practicum student doing music with him. These students needed people like Jay to practice with, Jay needed them, so what we're trying to do is to get the win-win. Now some of you who know our family story know that, very surprisingly, and very sadly, after all the thinking we did about how's Jay's life going to keep going when Rud and I die, Jay had a massive heart attack on January 7th of 2009, and died in a nanosecond. Nobody saw it coming on, there had been no problems with his heart, it was just out of the blue of the universe this happened. And it gives us so much comfort that, if Jay had to die, that he didn't die at the time he was kicked out of the only adult program in our community, and a time when he was so profoundly isolated and demoralized from that experience. We are so thankful that he loved his life, that he had a fabulous life, and that his last night, he died in the morning, he had just gotten up, his roommate asked him what he wanted for breakfast and he said waffles, and that was his last word on this earth, because he died immediately after that. The night before he had been doing music therapy with one of Alice Ann's students, and she told us, it was so amazing, that she was putting up her guitar, you know they were closing up for the evening, and she just felt they had to sing one more song and she said, Jay what do you want to sing, what's one last song, never knowing it was the last song of his life. And eerily, he said he wanted to sing 'Swing Low Sweet Chariot'. And think of the words of that song, 'Swing low sweet chariot, coming for to carry me home', that chariot came for him 12 hours later. And to know, for us to know, that maybe he had a premonition, maybe it was just, you know, it wasn't anything tied to, you know, what was going to be happening to him, but it gives us so much comfort to know that that was his last evening and his last song. And so, at his memorial service, I would love to show you this video, I've got one video left to show you and it was one that I just thought with time we had to leave out, but our dear friend Mike Raymire, who is the, now the Director of the Beat Center, did the eulogy and, let's, don't start this video yet Noella, and in that video Mike said that what he had learned from Jay's life, of

his home and his friends and his joy, of loving his life, so much of it built around music, what he loved most of all, Mike said what he learned is we're not in the education business, and then he said we're not in the rehabilitation business, as important as those areas are, Mike said what he learned from Jay is that we're in the dignity business. And it was the fact that all of these people who came together, Jay's village, approached him with such commitment, emotional connection, caring, that they wanted nothing but dignity for him. And I'll tell you folks, it's not dignifying to have a water gun shot in your face, but it's certainly dignifying to wake up in the morning, and for your roommate to, first question is what do you want for breakfast. Everything was done with dignity, and that made all the difference.

So, what we're going to see next, Jay, there was a memorial service at our church, that was just packed to the gills, celebrating Jay's life, and that evening we had another kind of dinner and celebration, so many of the fraternity brothers and the coworkers and the job coaches and the roommates and Jay's friends from 15 years of having this kind of life, Jay died when he was 41 and it, so I guess it was really more 16, 18 years, from his early 20s when this started, there was such a gathering, and people talked, told stories. Dela, who had been sitting next to Jay at the group action planning meeting that you saw, and when she was saying a strength she was saying Jay was the most rhythmic person she knew, Dela was the person playing the guitar at the singing that you heard and Dela was back, you know, 18 years later, leading the singing at that memorial service. But I want you to see how we closed the memorial service, I mean the memorial celebration. The service was at the church, the celebration was at a restaurant, at a venue in Lawrence, and I want you to see how we closed that, and I want you to see how the village grew over those 20 years. So, let's start this video.

>> [singing] This little light of mine, I'm gonna let it shine. This little light of mine, I'm gonna let it shine. This little light of mine, I'm gonna let it shine, let it shine, let it shine, let it shine. Everywhere I go, I'm gonna let it shine. Everywhere I go, I'm gonna let it shine. Everywhere I go, I'm gonna let it shine, let it shine, let it shine, let it shine. We've got the light of freedom, we're gonna let it shine. We've got the light of freedom, we're gonna let it shine, let it shine, let it shine.

>> For Jay Turnbull.

>> [singing] For Jay Turnbull, we're gonna let it shine. For Jay Turnbull, we're gonna let it shine. For Jay Turnbull, we're gonna let it shine, let it shine, let it shine, let it shine.

>> For our brothers and our sisters.

>> Amy McCard, when we had that meeting 16 to 18 years ago and I said what would be happening in 2005 and 2010, and you said we won't fit into this room, and I'll have to say that we were going to have this gathering at Jay's home tonight, but we couldn't fit into the room, and so we had to rent a place. Amy, your, the providence came true, and now we can go out and take that light into the lives of all of those people that Paul Marchand reminded us about. We thank you for being with us, we thank you for all that has been, we look forward to all that will be, we will keep Jay's legacy alive, we thank all of you who have traveled, we wish you safe travels home, and we will continue to share life's journeys together, God bless.

[applause]

Okay my friends, this was the person who was expelled from the only program in town. This was the young man where extensive change, so much change, was needed, where so many people thought it was unrealistic, and this is the life he experienced. And I want to go to a question that is, Janice, that you had, oh, not Janice, let's see who asked that question. Somebody, I can't see the name but, how did we get all of these agency people to come together? What I want to emphasize is that 85 about percent of all the people were not from agencies. That's, you know, we often think change comes from the professional disability and social service system. Most of the people, and the people who made the huge difference, were roommates and friends and musicians, and family, and the people where he would, Jay would go into the community and they would always be keeping an eye on him, people, some of the people there were owners of restaurants where Jay loved to go to, where they were always keeping an eye on him if he needed support. And yes, there were professionals who were very helpful such as Alice Ann from music therapy and Jane Wagner from speech and language, so we needed the combination of professionals and the ordinary citizens, but Jay's life in the community, in an inclusive community, it had to be built around his coworkers, his neighbors, the people of the church, his family, and those are not people of agencies. So it's how do we combine the wonderful professional expertise, and professionals can be so helpful in facilitating groups like this, in supporting people who have problem behavior, in getting the assisted technology that people need, so the professionals are necessary, but the family is necessary and the ordinary citizens.

So we are, I've taken more time than I meant to, I do see one question then can people contact me, I would be happy for you to contact me, my email is turnbull@ku.edu. That's Kansas Univeristy.edu. And I hope that you will use your handout, this PowerPoint will be available, and I would be happy to talk with you, for those of you who asked questions about siblings I would be happy to put you in touch with our daughters, and any way that Jay's legacy, Jay's teaching, you know, Jay's, you know it was Jay who would not be satisfied in the segregated program, it was Jay who had a vision that he wanted to live his life in such a more inclusive way. So, Phil and Noella, thank you for this opportunity to share, and I just hope all of you will know that the village is in your community, it's there, and it's for you to tap, for you to tap the young people from the church, for you to tap the groups for people at school age, the other peers in school can be so incredibly invaluable. The ordinary citizens are now in your community, and your job is to put together that village, to make extensive change happen, to truly make the impossible dream come true. Thank you very, very much.

>> Ann thank you, thank you so much, I, all of us here in CADRE are stunned right now and I'm fairly certain that there's folks all over the country who have the same experience, we're so grateful that you've shared such a inspiring personal story about your family, and help illuminate how powerful it can be when the community comes together, when the village surrounds your child.

>> Phil.

>> Go ahead.

>> Phil let me, when you say that it reminds me that, when Jay died, we had set up a fund at the KU Endowment Association in his memory, and the Endowment Association told us they had never had so many contributions for a single person, not so much in the amount of money, but in the number of contributions. And we got so many cards, hundreds of cards, from people throughout Lawrence, Kansas saying, you don't know me, but I've been watching your son around town for years, you know, and maybe they'd say they had a nephew with autism, and they always took great interest in seeing Jay out and about because that gave them hope. But again I want to emphasize, if he had been in a group of six or eight people going around on the little bus, it wouldn't have happened. They saw him, and they recognized him, and they cared about him, because they could relate to him one-on-one. So, a couple of minutes for questions?

>> Folks should feel free to type a question into the chat box or they can press pound six in your phone and ask the question, so we do have a couple of minutes to do that. There was a question earlier Ann about whether all of your meetings were in person or if you had any teleconferencing meetings.

>> Yeah, great question. We were mostly in our meeting phase on this in the early and mid-90s, you know, before teleconferencing was so available, that's a great way to do it, if people can't come. I mean I think there's something about being together, sharing food, sharing drinks, giving people a, you know, a pat on the back you know, but if people can't come the Skypeing is great, and also, you know if we were doing that now and Jay's sisters, one is in Los Angeles and one is in Chicago, then they could Skype in. So, you know, I think we should take full advantage of teleconferencing.

>> Great. Anybody on the line who wants to ask a call, who unmuted? Ask a question? Or a chat, type one into the chat. It's really so incredible, there's a, Ann do you see the question in the chat box?

>> Let's see. How specifically, wait is that? Let me go down to the last one. Often I work with single parents who are overwhelmed with getting through the day, any tips on how to help this model applied to a parent who is burned out or overwhelmed? And I think, in that instance, it's mainly the facilitator and other people in the group really surrounding that person who is depleted with help, and what I know, I'm thinking of a friend in Lawrence, a single mom who fits this description and she and I have been friends over the years, I've never facilitated a group for her, but it would mean so much to her, you know and maybe not to start with eight or ten people but maybe to start with three or four people, and kind of gradually bring in people who could open doors for her and her daughter, I think would be great. I think single moms who are feeling overwhelmed this is a perfect kind of support, and often, I'm remembering this particular person, that once I got involved in her life, and she had another, her daughter got a big sister from the Big Sister, Big Brothers, that this woman's mother said she felt she could be more helpful since she knew that there were two other people and her daughter wouldn't be asking her for everything. You know so, often the people, when other people know they don't have to do it all, then they're more likely to come forward, and some of these single moms might have some family members who were shying away because the single mom just needs too much. And with a group, they could be able to do one task a week, they just can't do ten tasks a week. So I think it would be perfect. And a great role for professional agencies is having the facilitators, and spending the time to get these groups up and running, would be such a great contribution.

>> Thank you Ann, and thank you to everybody for joining us today, we encourage you to click on the link on your screen to fill out a very brief Survey Monkey to evaluate today's webinar, I would really appreciate you taking a few minutes to do this. Our next webinar, entitled Creating Change: Student-Led IEPs as a Dispute Resolution Option, will be on March 15th from, at 11:30 Pacific time, 2:30 PM east coast time. More information about this webinar will soon be available on the CADRE website, we hope all of you can join us for that webinar. Again Ann, on behalf of all of us down here at CADRE, we're just so very grateful for you taking the time to share such a very powerful and inspiring story, and also to give such wonderful and clear guidance to folks out there, we really, really appreciate it.

>> And Phil and Noella, I really want to thank you for captioning the web, the videos. Folks this is the first time those videos have been captioned and CADRE did that, and you've been such a pleasure to work with and I appreciate being asked back after being a presenter last April, so I just feel we're reliable allies, and I'm very grateful to you for all you've done.

>> Thank you Ann, and we apologize for the echo problem, we're going to see if we can resolve that when we put the webinar up on our website, see if we can eliminate the echo on this video recording. So, again, thank you everybody for joining us and have a terrific day.

>> Thank you.