FEC Presentation

[ Please stand by for realtime captions ] Welcome. We will start in just about a minute. Settle in, grab a drink, whatever sounds good to you. Keep your whistle wet as they say.

Hello everyone this is Haley let me run through some important housekeeping items. All phone lines have been muted to reduce background noise, please keep your phones on mute during the presentation then we will unmute later for discussion. Please put your questions into the chat pod at any time. If you do have a question, please format it as a yes or no question. This presentation will be recorded and archived. The presentation will be posted in our base camp group. If you have any issues accessing materials, let me know.

Welcome everyone I met Megan I have the distinct pleasure of introducing two amazing presenters today. Teresa and Issac Baldry . Who are sharing their presentation of leased restrictive approaches to supporting individuals as decision-makers. Excited and I'm hundred percent confident that everybody will leave today feeling inspired and motivating as to what they have to share. So welcome Teresa and Isaac, take it from here.

Thank you Megan. So starting with introducing ourselves. Most of you know me as a part of the deaf-blind network and the project. But another piece I work on at the Royal Institute for inclusive communities is a project with the Department of Health and Human Services and children's special health services. Under both of these projects is a component for families which is meaningful for me because I consider myself a family member of an individual who needs support. I started that work back when she was three years old.Hello I am Issac Baldry. The work that I do as a self advocate and youth mentor. The reason I wanted this chance to speak with you today was to share an example of somebody who uses less restrictive tools and why. My slide has a few pictures of me in one. I am working and I am giving a presentation using my computer to speak for me. And in the other I am showing the screen of my phone to Patrick. He wanted to learn more about the app I use to communicate. He wanted to know how I could communicate when I didn't have something attached to my chair. I wanted to make sure you could see me, since this is a presentation you're already getting to hear me. Because if you can hear me you've already made assumptions and have already noticed I'm not able to speak verbally. Now that you have pictures you may have noticed the wheelchair. If we met in public and I wasn't sure who you were or didn't want you to notice me. I might not even look at you, secretly hoping you were not looking at me either. People might choose to believe because they see the wheelchair, that my brain does not work. Because sometimes I choose to be quiet or not noticed when I don't have opinions. If you got to know me, you would learn that I have a wicked sense of humor and I love a play on words. And as far as opinions, there is a reason they call me bossy or picky. I know what I want. And if I know you, you will wait for me to tell you. I'm thinking all the time. This is one of my favorite quotes. Presume competence isn't just a catchy hashtag. Is a philosophy. It's a way of life and faith and love. It's relieving in our kids and in so doing, enabling them to believe in themselves.

All individuals can make choices about their lives. The level may vary and where they choose to make decisions might very. I wanted to show an alignment with the transition recommendations already in place so let me walk through some of what's already posted here. Under training and technical assistance there's provide information, training and technical assistance, that raises expectations for a meaningful adult life. And work experiences there's individualized to student's strengths and support needs. We can talk about how you can get to those pieces. Third, advocate for community activities and living. Advocate, to have community activities and living meaningful participation and membership in their communities. Fourth, school and adult agency collaboration. Seamless transition to the adult life. Fifth, qualified personnel. The hearts of sport person centered planning. Six, educate families. Educate and inform families on the transition process, adult laws, and services. Rights and long-term supports. To talk in just a moment about rights. A lot of times when we talk about guardianship, for restrictive options, those components have not kept up with civil rights within our country. Disability is a natural part of the human experience that does not finish the right of individuals with developmental disabilities, to live independently and to exert control and choice over their own lives. That's from the DD Bill of Rights. Over the last few years we've done projects and books that are outstanding to read when you look at how all these pieces connect. One is called beyond guardianship. Alternatives that promote greater self-determination and another is called turning rights into reality. How guardianship an alternative impact the autonomy of people with intellectual and developmental disabilities. So if you're looking for a place that can provide you with more information I always like to have those available. Another piece to look at when talking about this is Olmsted and how -- homestead. As well as the ADA integration mandate. So we got a lot of lost the support this work. It's just that where we are varies from state to state. So here's our first polling question. Are you familiar with the term guardianship or conservatorship. It looks like everybody was familiar with guardianship. And conservatorship. So that's helpful because in each state that language can be different. Where we are from and Montana. Guardianship as of the person and conservatorship is of the estate. I'd like to spend some time clarifying that for this presentation, we are talking about adults guardianship. Looking at supporting an adult who becomes 18 and at 18 were not talking about children under the age of 18. This is often an emotional period. Guardianship can be an emotional issue in that people view there has to be a right way and the wrong way. So there probably really is a spectrum of support to consider and how might different pieces match with what an individual needs and has skills in. Most guardianship referrals come from schools or from the medical community and they are really more concerned about the process of what needs to be in place versus how the decision and process impacts the person who will now be placed under a guardianship. And another piece that's really important for parents is the hopes and dreams bullet. When a family member has an individual come into their lives who has a different house, we are told sometimes that we can be measured against the typical. When you don't have a way that's typical. We often eliminate the ability to limit that expectation. Families have to build new dreams and still have new hopes for a future when there really isn't a pathway that shows them all those responsibilities. Trying to make sure that people understand that there are dreams to have and hopes to have. The other piece is that families often believe they need to be a parent forever. And when they take that perspective, it takes away somewhat of recognizing that this person has now moved on to being an adult and what might need to be in place as just respecting them as an adult. Did we work on skill building. If not we may not have taken the time to develop skills. We might have a view that we need to protect them and sometimes that can be in direct contact with the dignity of risk. Are shielding that person from a real life experience and if so, why. Is it that we are afraid that they will fail are we afraid they won't learn from that failure. We always have to keep people safe but we also have to allow for that growth from learning. Let's talk about capacity. Realize that capacity is fluid. It's something that changes based on a lot of variables. I chose this picture because if you're an individual with Alzheimer's, it's established that capacity can be impacted by the time a the collet son Downing. If you're working with someone who's older by the time they get to later in the day. The capacity is not as strong as earlier in the day. In our family we have an individual with Alzheimer's. There are days when they have a good day and they just need somebody to support that their voices heard and they have days that are bad days. On those days they need to make sure that choices and decisions move forward in the way that they would have wanted based on their values. But somebody needs to be the support in their voice. Another piece that can impact capacity is the opportunity to learn. You can't gain skills if you're never exposed. So whatever the path is you choose to take on. If you don't have the experience, your skills are not there. It's only through practice that opportunity can be exposed that you develop those skills. That goes back to the dignity of risk and the opportunity to learn by mistake. Sometimes the most important thing that we learn our when we say that that didn't work. What was it that didn't work and how if I want to do this again, will I do it different. And another piece that greatly impacts individuals especially around aged 18 is the opportunity for growth. That change between 18 and 25. For those of you who've experienced so the person that we made at 18 might not be the same decision that we would make as we get older. For college students you might see tremendous growth in who they are for all of those opportunities for independence. By the time they are graduating the adult who they have become might be a completely different person but we don't necessarily give individuals with disabilities, the same opportunity for experiences and to mature. To change what they know and how they want to make choices. There's a difference between legal capacity, mental capacity and functional capacity. In legal capacity we need to respect that each person has that, functional capacity can go back to what are the opportunities or how does your opportunity impact the movement of your body. Have you heard of these restrictive options or alternatives to guardianship. Some people are familiar and some of never heard of these options. So were hoping that this information as we move forward in the knowledge.. Tell us little bit about which ones you're familiar with or know about. Powers of attorney Weatherby for help. Will talk a little bit about that today and we hope to give you a broad idea of what is potentially available and how that can be considered a support. One piece if you could help me your posting this closeout was pulled now thank you everybody. Always start from the point of what is will the leased restrictive what takes away the least amount of right and choice from the person that is available and consistent with that person. Not that we want anyone at risk. Will -- under leased restrictive for decision-making we also have advocacy forum and a shared copy of that in the toolkit is available. There is an important piece that the individual retains full independence and full decision-making powers getting the support as needed. We can talk a little bit more how that's needed. Less restrictive. That goes on to the power, going on to familiar items. Representatives for high-security. The difference when we moved to a less restrictive tool is individuals retain some but not all control over decisions in their lives. A representative is designated to make this decision for an individual in a specific area. The powers of attorney and the represented items specifically. Were talking about limited guardianship which might be for a period of time or a temporary guardianship the guardianship could be looking for specific area where the individual meets that level of support. So Guardian is limited under these two as the decision-maker with individual. Based on what needed by the individual. The order for the guardianship is tailored to the court. Under the most restrictive we have what's called a full guardianship are plenty are guardianship. In that case, the Guardian has a full decision-making control over all areas of and individuals life and it requires the court order. In some states this impact whether or not an individual can vote. Would you be voting? So why should we look at alternative the guardianship. Looking at these less restrictive options. From the national guardianship Association. Turned to guardianship. So whenever possible prior to the commencement, will -- allowing for potential growth terminating rights unless that's absolutely necessary. Research from Jamison shows us that individuals, people with disabilities who demonstrate greater -- teachers -- shown that people with disabilities who exercise greater self-determination have improved employment and quality-of-life are better problem solvers and are better able to resist and avoid abuse. For what choices they have and how to protect themselves. It doesn't necessarily provide the protection intended. And a new piece based upon where we are before Covid-19 was that individuals with disabilities might be a part of the first generation to outlive their parents and potential guardians. So, a plan needs to be established and considered for when the parent is no longer an option as guardian. When we are talking about decisions and choices. Some decisions are big and those tend to be the ones were thinking about guardianship when they need to be in place. Sometimes we are not giving individuals the opportunities to make choices and decisions throughout the day. And how does that impact them giving back the right to have a voice in what they want to choose. To make decisions as an adult. Sometimes to say nothing happens until your decision is made. How does that empowering to someone when you give them back that power. When we are making decisions we really need three components. We need to be able to take in the information. It should be provided in the best way for individuals and we need to be able to make a decision about that information once we have it all. We need to be able to communicate what our choice and decisions are. I want to talk just for a moment about how do each of these or each of us make decisions. It's never too early to start the conversation of how we can provide less restrictive options for individuals. How we let them know that their voice or their opinion or their desire for what they prefer is important and that they have the right to choose. As someone's becoming closer to 18. Do we allow time for them to develop and learn the tools that they need. It's important that they know what the tool is for when to use it and how to use it. Isaac will share some of that in his story. Time may be needed for the individual to develop the signature. To understand what and where do I sign. By signing my name, what does that mean. This can mean using a stamp. If that's what the person designates as their decision. Remember that to use these tools, they do not go into effect until they are 18. A lot of times we look at setting up before they turn 18. Were teaching them what the tools are for and how they would use them. Helping them also understands that this is a part of that transition to becoming an adult. Once you an adult the tools could be something that you use and the signature as an adult would be legal. So I think alternative and Isaac now.

In this next slide I want to share with you about becoming an adult. It's been a while since you've turned 18. I was excited to turn 18 to become my own boss. And got three older brothers we made a big deal about becoming an adult then once you're an adult you got to make your own decisions. Somehow when you turned 18, magically, you didn't have to follow rules anymore. It was going to be my turn. Because I have a disability I had to learn early on and I had to stand up for myself. I had to communicate about what I didn't think that was fair and what I thought was wrong when I was excluded and had different rules because of my disability. I had found a way to be a part of the conversation since before it was too. Just like everybody else. I stood up for myself when I was told I could not be a part of doing something. Twice before I was 18 I had to file human right complaint but now, because I was going to become an adult. There were people who said I needed a guardian. This student make sense and we'd have to find another way. I'm glad that I got to be a part of helping to create tools for people to have support and still be the boss of their lives. I will share more about what tools are used as we go through that presentation. I want to tell you about my pictures. These are from an adult decision that I made. I've always wanted to ride in the sidecar of a motorcycle. So I was given the chance. That's me ready to ride. We are on the annual bikers ride. The guy driving the motorcycle is a friend who flew in from Las Vegas just to drive for me. The other guys play in a rock band that came for the concert after the ride. This is something I choose to do not something I get permission to do.So when we look at helping someone make decisions. It's important that we get to know that person. What are their skills, what are their strengths. What are their concerns. What are their fears. What do people around them season skills and what do people around them become concerned about or afraid of. I have listed a few tools on the slide one called the practical tool, each of those letters stands for and component that was developed by the American Bar Association. I really like that tool and I find it helpful in guarding people over all the areas to be considering. The ACLU has come out with a great tool of when do I want support. That can often be helpful when looking at all these areas and how I want to be supportive. We want to touch upon the growth component in that in the tool kit that's available at the Institute, we can put a link into the chat later. There's the growth cause that allows you to take a look with what are focusing on for the next years we found that families needed information in three big areas. For medical and financial. Some people are familiar with that and some have never heard of it. Thanks Haley let's and that pole. So supportive decision-making goes back to being one of the least restrictive options is a process rooted in the belief that all people have the right to make decisions and choices. As a tool supportive decision-making is not specific to one form it's key that the individual directly impacted by the chores or decision is based on their needs and wants and preferences. So it could be that it's a form filled out and in the resources towards the end of this presentation There are some model forms. It could be that a model form is used. In the work that I do I often provide some model forms as samples and people tend to merge and choose the pieces that are meaningful to them as a way of documenting how they want to be supported. Individuals using people that they choose, friends and family members or professionals to help them go back to understanding that information. Making sure they have the information piece and what options need to be considered. So that information piece again, and on this piece consider that everybody needs support, at some time. If we think about how we make decisions, I am terrible when it comes to cars. I know where the gas goes into key goes and I have moved up to where I can check my oil but my skill set is low, though I know where to go to and support so that I can get the information, understand the consequences of my decision, make a decision, and vocalize my choice. I don't have to rely on just the knowledge that I have. We all have areas that we are not as good at making decisions in. Yet, when I do it looked at I'm using my resources. For an individual with a disability when they start reaching out for help, our first thought is they can't do it we need to replace this. Instead of allowing that opportunity to be supported. Things that are important to remember is that it's a voluntary, they choose this. It can be customized based upon what the individual needs support with and how they are choosing. It can be a team that can be one person. People need to be able to understand the information provided and help if they choose, in communicating it. The goal is that the individual retains control of their life develop a plan and then share it with people who need to know

The next piece I wanted to share was how are you supportive decision-making. I can spend a lot of time thinking on things. Sometimes too much and then I start to worry. I need to move things forward in a way so I don't get stuck. I start with the decision I have to make, do I have something that I'm worried about. I identify what I need to address then I talked with my mom or sister about what I'm thinking on. Then we decide if I have enough information. If I do not. I might need to go on the Internet to get the information or identify someone that I need to call. If I'm going to make a call I need to decide if I want to ask questions that someone else is going to ask and that I'm on speakerphone. Usually want to ask the questions. I have to than program what I want to know. I like to have somebody with me when I make a call in case there is a problem. I now even have programs, please do not hang up on me. I use this computer to speak. It works most of the time. Before I am off the phone I make sure I got all the information I need. That I have to think about what I've learned and new problems and do I now have more possible solutions I've not thought about. Am I ready to make a plan and if I have a plan to meet anyone to help me. If I do, have I told them what I need from them. Sometimes I just like to talk through my plan, so others know what I want to have happened. Sometimes I need to practice plan so I'm sure it will work. I feel better when I have a plan and know what to expect.

Let's jump into these three areas of family. Talking about education first. Under this education first piece it could be that nothing is added or done but we just look at how can we make sure that they are a part of the team and a part of the decision and how are we giving them the opportunities to provide choice in their voice. In the forms that we have those educational advocacy forms. Those very as far as across the state and Montana develop the forms that we have with disability rights Montana. Are advocacy organization and that's on the leased restrictive. I'm jumping forward with Isaac to share how he uses his forum.I used that form when I turned 18. I scheduled an IEP meeting for after the Christmas break. My birthday is just before Christmas. I brought my form to the meeting and let the conversation about what I wanted. I let them know what needed to happen and what needed to be signed and who should be invited if I needed or wanted support.

An important piece for Isaac was he did not want to sign things without someone else. His forum instructed the district that there was anything that he needed to sign that his advocate would sign with him. The next piece when we moved to less restrictive we talk about an educational power of attorney. One that's limited in scope and specific to how somebody will make decisions for another person. The next moving would be limited guardianship for educational purposes. And adding how impressed I've been with how colleges and secondary look at supporting all the adults not just people with disabilities. So being in touch with the college or university about what is available so that they have information and help in understanding the information or help in accessing information while they are developing skills. That's a change that I've seen over the last 10 years and it's much appreciated. Helping adults be more successful at school. Under medical. We can have supportive decision-making for how an individual wants to make decisions around medical. Assisted technology can be a leased restrictive support. If you're an individual with diabetes there are apps to help with that and reminders. In Montana we have is he's called the designated caregiver. And digital can be appointed to receive information when somebody has had a procedure, nothing more has to be done. It's a designated caregiver. Within the HIPAA release, you can include a phrase that says for decision-making purposes to the form to make it a decision-making tool. The next steps would be medical advocacy forms and we have an example of that and how Isaac uses this form.

I like my medical form. It makes me feel like I am the boss. I started using it with doctors the first month I turned 18. I took the form with me to my primary doctor and to the specialists that I see. I also keep a copy at the local hospital in case it is needed. The last place I have it is on my iPad. In case I needed while I travel. Giving this to doctors helps let them know what I expect. Sometimes the medical information is not good news. The form does not make it easier to make tough decisions about surgery. But I felt better that I made the decision. My form helped make sure that information was given to me and that I understood the positive and the negatives. I make all my medical decisions. I would not like it if somebody else decided and then told me what was going to happen. My form let's doctors note to talk with me. If a support person is in the room with me to help if I want.

Moving more towards the less restrictive would be a healthcare specific a healthcare power of attorney. Montana has new forms and multiple states have the options to exist another piece is called advanced directives that often deal with end-of-life choices have information and links that we can share. In Montana we have a Montana mental health advance directive. So while an individual is not in a crisis situation helps them to plan for what they like healthcare to be like when they are in crisis. It's more restrictive being a limited guardianship specific to medical care. And moving on to financial. One of those areas that we sometimes skip providing opportunity is sometimes within financial. We don't necessarily get that opportunity for financial literacy. The opportunity to earn money and to decide and choose how you spend your money can really be important in understanding how and what money means to you. When we talk about minimal supports for an individual under that less restrictive. It could be as supportive decision-making plan that goes through how you make financial decisions. It could be the debit card or store card provided to individuals so that they can make purchases but only to a certain amount. That they have that choice within that range based upon what was determined and agreed upon as to what they felt comfortable in learning to use. One other piece that sometimes passes is considering how are the tools that were teaching an individual provided in a way that moves forward into the real community. A lot of times we look at teaching the dollar over method and we are doing that on a worksheet. What are we looking at creating a number line that could slip into a wallet it's really something they can pull out and use in a day-to-day situation to help them understand and use the concept is still have that tool available to them. Next steps would be under that leased restrictive. Maybe it's a joint checking account where two signatures are needed. It's limited just to the financial peace. In Montana we have some forms for that. There are trusses and conservatorships I don't know if any of you owe are familiar with, this is a link to the national able resource Center. If you're not familiar with them. It's a great tool for allowing individuals to save money even when they are on tested benefits. Another piece that impressed me for the consortium that Montana belongs to us that they have an agent authorization for how people could be supported in using the ABLE account. They plan to head to have that piece ready.

Isaac regularly makes contributions to his ABLE account. And we are able to make contributions as well. It allows us to claim estate income tax deduction. All of them are different in every state. Some states don't have them but your still able to get that account in a different state. You should compare them. There's great resources at the national resource Center. So taking a quick step back all the way to the national and state level. When we look at less restrictive options and look at the national level. There's a piece called the uniform guardianship conservatorship and other protected arrangements at. A few states like Texas and Maine have used this and incorporated it into their own state law. It gives will guidance on how to best support and value a person who might be in need of support. The national guardianship Association of got that link here. It provides guidance on the national level. There's also a tremendous resource called the national Center for supportive decision-making. They have information available collected across the country. Videos and model forms. They can really have you brainstorming we should consider in supportive decision-making what's available in your estate. They are a tremendous resource. When we start looking at additional components there's a few pieces I'd like to share in regards to the form. So it depends on your estate. Whether or not notarizing a form makes a difference. In Montana though not required. Often when an individual presents a form that's been notarized. It seems to have some more weight. People value it more. It's important to keep track of who your sharing your forms well. If you're sharing a medical advocacy forum or one that we didn't talk about with other service providers pick to have a list of who has what form, both because you don't want to just give them out to anyone. You should be intentional as to who need to have that information. And if the form is updated because of growth or new skills. Who you need to provide a new form to. A running list of who you've provided those forms with. In the tool kit we address and respect is talk that I value greatly. Will be included in the toolkit so take a look at that. It all goes back to how does it impact an individual when we provide them with respect to how does it impact us when we are given respect or not. Does it change how we view the other people or how we view ourselves. Unfortunately in our world today end-of-life decisions have become much more in front for the work that we do. So are we including people in those conversations as to what they want, what matters to them. What other values. And there's a piece with the toolkit for that. There's a national state piece that has pieces for each state that I can share. The last piece I'd like to talk about was driven by parents. When we first developed this toolkit the piece they said we didn't include was undoing guardianship and a restoration of rights. In Montana. That again becomes a court process to undo a guardianship. If you have someone determined to be incapacitated. You have to use the same measure as to whether incapacitated I can't share the intensity of that the right is taken away sharing how to get it back. And something we should always consider some more resources here and the right to make choices. Entering decision-making for people with disabilities. This is an easy read is a great set of YouTube here's the alternatives to Guardian toolkit. There's a beautiful work around futures planning's. If you've got a chapter you can get in touch with them but here's the link for you to explore. And the disclosure. This is for the Montana transition employment project gets funded in whole or in part under a contract with the Montana Department of Health and Human Services. The statements don't necessarily reflect the department we hope this information has been helpful for you and I think we can move on to some questions and answers.

So Haley will unmute everyone's phone lines and if you can put your WebCam on as well so that Isaac and Teresa can see their audience.

Thank you to the captioner your services are no longer needed. I will unmute the line so just give it a minute. We will stop the recording.

[ Event concluded ]