

**NE GENETICS COLLABORATIVE  
SPECIAL EDUCATORS PROJECT  
FOCUS GROUPS**

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**The University of New Hampshire**

**Survey Center**

The UNH Survey Center is an independent, non-partisan academic survey research organization and a division of the UNH College of Liberal Arts.

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## Contents

Introduction.....	1
Participants.....	1
Major Conclusions.....	2
Specific Findings .....	3
Moderator’s Guide .....	10
Transcription – Killingly, CT .....	14
Transcription – Somersworth, NH.....	41
Transcription – Burlington, VT .....	61

## **NE Genetics Collaborative – School Focus Groups**

### **Introduction**

The UNH Survey Center conducted a series of focus groups with elementary school educators in collaboration with the New England Genetic Collaborative (NEGC). The purpose of the groups was to test reaction to a new web based tool designed by NEGC to provide practical information about children with genetic and metabolic conditions to elementary school teachers. Three focus groups were held with staff from elementary schools in various New England locations. Groups were conducted on February 22 at Killingly Intermediate School in Killingly, Connecticut, March 11, 2010 at Maple Wood Elementary School in Somersworth, New Hampshire, and April 7 at the Flynn School in Burlington, Vermont. Eight people participated in the February 22 group, eleven participated in the March 11 group and seven participated in the April 7 group. All groups were moderated by Andrew Smith of the University of New Hampshire Survey Center and lasted approximately one hour.

### **Participants**

Schools were recruited through members of the Dissemination, Information and Marketing (DEM) workgroup of the New England Genetics Collaborative in partnership with the University of New Hampshire Institute on Disability and the UNH Survey Center. Schools that agreed to host a focus group recruited elementary level teachers, special educators, para-professionals, OT, PT and speech specialists and school nurses for the focus groups. The group composition is as follows:

#### **Killingly, CT (February 22, 2010)**

Position: Five special educators, one speech pathologist, one occupational therapist and one physical therapist. (8)

Experience with genetic or metabolic conditions: Ataxia, Fragile X, q22 deletion, Downs's syndrome, Williams Syndrome, fetal alcohol syndrome, cerebral palsy

**Somersworth, NH (March 11, 2010)**

Position: Six classroom teachers, two special educators, one para-professional, one speech pathologist and one occupational therapist. (11)

Experience with genetic or metabolic conditions: 11.2 chromosome deletion

**Burlington, VT (April 7, 2010)**

Position: Three classroom teachers, one para-educator, two special educators, and one school nurse. (7)

Experience with genetic or metabolic conditions: Down syndrome, Rhett Syndrome, Prater-Williams, cerebral palsy, celiac disease, munchkin-CMT, Diabetes

**Major Conclusions**

- The overall perception of a genetic disorder information website is that it would be very useful to those in the classroom, special educators and in the future to parents and families.
- Some major buttons should be added that would fill a need not currently available on the proposed site.
- The site would need aesthetic changes and technical refinements.
- The platform needs to be scalable toward additional populations, additional conditions and additional characteristics such as age or grade of student, and whether it is a parent, teacher, or special educator using the resource.

### **Concerns in the Classroom**

To begin the discussion, participants were asked to describe concerns that should be addressed to feel more comfortable educating children with genetic or metabolic disorders. Participants cited concerns about how the disorder would affect things such as learning, medical, support systems and other issues.

#### Learning: (Learning abilities, lifetime and educational goals)

- “How does it affect learning, if it does”
- “What can I do, what can’t I do? ... Like how far do I push this child?”
- “Figuring them out behaviorally ... when they come to me, they’re in a better place and they’re ready to academically learn, and then you feel very stuck about what type of a program or information is out there to best suit them”
- “Also what are the ultimate goals for the child, what can you expect in adulthood for a child w/ a particular syndrome”
- “...about the prognosis, what are we preparing, what are lifetime goals for these kids”

#### Medical: (Dietary restrictions, endurance, safety, contraindications, modifications and protocols)

- “Medically I mean things like allergies. You know, whether it be food or whether it be things in the environment or the other thing that I was thinking, are they prone to seizures?”
- “What’s the medical background, or what has happened up to this point, what should I expect, what’s it gonna look like?”
- “And if something happened, we’d need to have protocols or just a game plan for what to do.”
- And we have the kids, we have them here for 6 hours a day, so they go through eating in our classroom and they go through gym, and contact with other students, contact with the outside during recess, so there’s a lot that can come into that area and you can’t always control all of it, so you know, what specifically needs to be controlled to keep them, like [woman] said, safe.

**Support Systems:** (In-school supports, family life, outside specialists)

- “Who on staff should be aware of that student and what they need”
- “I think also another concern for a teacher is will this child have help aside from us, because it’s too much to ask for a teacher to have to deal w/ the medical needs of a child.”
- “Also a list of people that you’d call in, specialists...”
- “The other thing is the parent piece. I want to know, how has... How has this affected the family life?”

**Other issues:** (Child’s ability to communicate, information to help communicate the child’s condition to other children, and information in general on the condition)

- “...social is a big, big, big key.”
- “Just how does the child communicate that they understand and how do they communicate what they want, what they need”
- “I’d want to know, is how to present it simply to the other children. Because you have to say, ‘this is a child in our class who needs to be included in this way, and these are the things not to worry about.’”
- “you can just type in anything and Google pumps the information out for you, but to have something sort of prearranged so the link is there”
- “up to date, most current information without being overwhelmed”

**Information Sources**

Participants were next asked to describe where they would get information, what the best vehicle for that information is and what type of information they are most interested in. Participants cited IEP’s, parents, medical professionals, books and the internet as the places they look to get information from. The vehicle for the information is generally described as electronic – internet, PDF, listserv, etc., some participants mentioned books, and other mentioned getting verbal information from colleagues / peers, parents, and physicians. Most participants cited they would want both practical information for the classroom and specific information about the disorder. Among the typical comments included:

### Where to Get Information

- “The school nurse”
- “Woodbine House Publishers. It’s a special ed. publisher”
- “Case manager for that IEP”
- “I go to the parents and the doctor”
- “I do the internet a lot”
- “Google, absolutely”

### Best Form of Information

- “I usually think of the internet as like the first”
- “I always start with the IEP”
- “You can get PDF’s”
- “Not chat rooms, but like blogs or things ... other teachers giving ideas back and forth to each other that sometimes are helpful, what’s going on in their classrooms, bouncing ideas back and forth off each other”
- “I also go to Merck’s Manual”

### Type of Information (Practical or disease specific)

- “practical first, and then I would just out of curiosity want more”
- “By knowing more about the disease, I think you’d understand the student better. The whole student, at home and at school, and just what their life is like”
- “I would like both.”

## **Overview of Web Tool**

Participants were shown the mock-up of the web tool for three different genetic disorders, PKU, 22Q deletion, and sickle cell anemia. Participants were encouraged to ask questions and/or make suggestions during the demonstration. Below are some of the more frequent suggestions:

**Functionality:** Ideally, participants would like to see the tool expanded to provide information not only to the teacher, but parents, special educators and segregated by age groups. In addition, it was recommended that information be available to print either all of it or selected pieces of it as PDF files.

- “I think a 1-2 year breakdown would be better [for ages of students]”
- “if something is not needed for that particular disorder to just have them [the button] dimmed, so there’s no link to it”
- “What I would love to see is on this front page of this disorder... to be able to have a print all materials button.”
- “Having it underlined, where you’d click on that [word] and get the definition or an English definition.”
- “Would be helpful to have English up there rather than the terminology”
- “the option to both type in the name ... and have it scroll down”
- “something on the website where people can provide feedback or ask questions”
- “Links ... for additional resources under each category”
- “This shouldn’t say increased absences, it should say absences. It’s just like the judgment of easy fatigability”

Features: Participants expressed a desire to have more specific and practical information in the form of links, forums or educational strategies. Participants also would like information about who they should be talking with about a child with a particular disorder.

- “It’s often nice to have who else might be involved in this process. Like ... if the child has PKU, ... there’s probably a nutritionist and the school nurse [involved]”
- “If there’s no emergency plan, then what, so what’s the big whoop? What is PKU? I’ve honestly never heard of it, so I wanted to know what happens if an accident happens.”
- “It seems very basic actually”
- “More ... strategies if there are some available would be helpful”
- “Because I think this is very good, but it gives you a very general, but okay, so now I know all this stuff, so what do I do with it”
- “Videos of people with [disorder], video links or pictures”

Additional Buttons: Participants mentioned some topics for inclusion as “major buttons” such as sensory, social, home and family and a button for additional resources.

- “Maybe instead of like sensory supports, supports for pain, more of you’re thinking of just what to expect about their... Hearing, vision.”
- “...I think the social piece is so important for all our kids nowadays, and I think that needs to be a button”
- “Home and family supports”
- “...a button [for more resources] that was ... specific to this [condition]”

Overall reaction / Usefulness in the classroom: Participants were asked their overall reaction to the tool and whether they felt it would be useful, what they liked best and least about it, who should have access to the tool, and what is the best way to let people know about the tool.

- “Definitely.”
- “It seems very easy to use”

### Like best about it

- “Organization of it.”
- “It’s like a frequently asked questions”
- “Format is really readable”
- “Having those links for some of the vocabulary”
- “Geared toward teachers”

### Like least about it

- “It’s good information if you know nothing about the disease, but it’s also very basic”
- “Just to make sure it’s accurate, and that you have the right people working on it.”
- “Making sure that it is seen as a valid thing”
- “Have the ‘last updated’ statement on [the webpage]”

### Who Should Have Access

- “I think everybody”
- “Anybody who is interested.”
- “After school programs, our school nurses”
- “Coaches.”

### How Often Use it

- “If those links w/ more information were on there, I’d probably be on there at least weekly”
- “I’d be bookmarking, if there were more recommendations, I would be going to that regularly and like questions to ask at meetings”
- “And if there was that discussion forum, because they are so rare.”
- “Until I know what I need.”

### How it should be Rolled Out

- “Principals and superintendants hold conferences as well”
- “I think a workshop”
- “District teacher professional development”
- “Vermont Principal’s list”
- “Vermont School of Nurses Association.”
- “A poster in the teacher’s room might. If I kept seeing this, you know, if you have a child with any of these, here’s a resource for you”
- “NEA NH”

## **MODERATOR'S GUIDE**

## Special Educators Project Focus Group Moderator's Guide December, 2009

### INTRODUCTION (10 minutes)

#### Introduce moderator

**Review purpose of focus group discussion:** “Thank you for coming to this discussion. My purpose is to get feedback from people involved in special education about the usefulness of a web site designed to inform you about the educational and other needs of students who have genetically based diseases.”

“We’re only going to use first names during our discussions today, and you can be assured that no names will be used in the report. There are no right or wrong answers—your honest feedback is what we’re looking for. Occasionally, as your moderator, I will need to move the discussion along, so that we can end on time, and sometimes, I might ask if you agree with what is being said—or if you disagree.”

**Introduce note taker:** “Tracy will be assisting me today in taking notes and helping with some of the logistics of the session. We are also audio-taping this meeting because neither of us can remember everything said by everyone, and we need all of your input for our report. To help with that, please voice your opinions one at a time.”

**Participant introductions:** “I’d like you to introduce yourselves to the rest of the group by stating just your first name, your position, and how long you’ve been in that position.”

**1. STUDENT EXPERIENCE (10 minutes)**

“I’d like to begin by asking your experiences with children with genetic or metabolic disorders ... for example, students who have PKU, 22q deletion, sickle-cell anemia, or other genetic or metabolic disorders.”

“Have you had students with any genetically based diseases?”

“Do you currently have any children with these diseases in your classrooms?”

**2. CONCERNS IN CLASSROOM (10 MINUTES)**

“What are the concerns you need addressed for you to feel comfortable educating children with genetic or metabolic disorders?”

**3. CURRENT INFORMATION SOURCES (20 minutes)**

“If you needed information about a medical condition, and any special implications for assisting these children, where would you get information?”

“What is the best way for you to get information about educating students with genetic or metabolic disorders, for example, brochures, posters, by email, or a web site?”

“What kind of information is more important to you ... practical knowledge concerning having students with these disorders in your classroom or more specific information about the genetic bases of the disorders?”

#### **4. REVIEW OF WEB TOOL (30 minutes)**

“I’d like to show you a prototype for a web site that is being developed to provide information about children with genetic or metabolic disorders to educators. Let me walk you through the design of the web site and get your feedback.”

#### **WALK THROUGH PROTOTYPE**

“What is your overall reaction to this website ... would you find it useful or not in your classroom?”

“What do you like best about it?”

“What do you like least ... that is, what are the biggest problems with this prototype?”

“What could we do to improve it?”

“Who should have access to this kind of web tool?”

“How often do you think you would use a website like this?”

**TRANSCRIPTION  
KILLINGLY, CT**

Killingly, CT  
Focus Group-NE Genetics Collaborative  
2/22/2010

SMALL TALK

Andy: Let me introduce myself. My name is Andy Smith. I'm the director of the survey center at the University of New Hampshire. I am a Political Science professor there, and this is Tracy Fowler who works with me. She is going to be taking notes and just kind of keeping track of what's going on today. How many of you have ever been in a focus group before? Because that's what this is. Basically, the idea here is, the purpose is to get feedback from you, from people involved in special education about a web tool that the New England Genetic Collaborative has designed, and we're at the point where we're kind of field testing it to make sure it is doing what we hope it does. It is designed for teachers, classroom teachers who have children who have genetic disabilities, genetic conditions, and to kind of give them practical advice or information about what to do, what to expect, etc. So, what we would like to do today, is I am going to have some general questions about some of your experience and background and so forth, and what you're doing right now, where you're getting information, but again, there is no right or wrong answers. We're just looking for kind of, from a potential users view of something like this, what works, what doesn't work, what you'd like to see, etc. So, what I'd like to do to start off with, is, and I am taping this. This is these handy new little digital tape recorders, so you don't have to carry the tape recorder anymore, that'll record like 6-8 hours worth of digital stuff, so it makes our lives much easier than it used to be. But because we're taping it, and it's only going to be so we have an accurate reflection of what people say, I'd like to just have us go around and introduce each other, but just use first names. No names are included in any report or anything like that, but I don't think that there's anything that we're going to be talking about today that's particularly sensitive on those sorts of things. So, again, I'm Andy Smith from the University of NH.

Sandy: I'm Sandy. This is my classroom, special ed in 5, 6, 7, 8.

Gail: And I'm Gail, special ed, 4<sup>th</sup> grade.

Trish: I'm Trish, special ed, IA with Gail in 4<sup>th</sup> grade.

Woman: And a parent.

Trish: Yes, I have a son with autism.

Andy: So do I. Mine's 11, so we'll have to talk.

Donna: I'm Donna, I'm a physical therapist. I do 3-21.

Kelly: I'm Kelly. I'm a K-4 literacy coach.

Karen: I'm Karen. I'm an occupational therapist in 3-21.

Marcia: I'm Marcia. I do special ed, 3<sup>rd</sup> and 4<sup>th</sup>, this year I'm 3<sup>rd</sup> grade.

Gretchen: Gretchen. Kindergarten special ed.

Andy: Okay, well, thank you very much, and hopefully we'll be able to go through this pretty quickly and get everybody out on time. Um, just to begin with, I'd like to just get some information from you about your background in dealing with kids with genetic or metabolic disorders, some examples that we would use, whether it's PKU, or 22Q deletion, or sickle cell, other genetic or metabolic disorders. And for this purpose, I don't really want to talk about autism which is something this will get scaled out to near the end, but have you had experience with dealing with children with genetic or metabolic disorders? Most of you have?

Woman: Well, I've worked for the state of CT for quite a few years, so I've seen all those and a lot more.

Andy: What are some of the other disorders that you've had to deal with?

Woman: Um, ataxia, fragile X, you know fragile X? Now 22 deletion, is that Downs? Cuz I've had 18 and 22, and I can't remember which is which.

Andy: I'm a political scientist, I have no idea about the...

Woman: Well, I've done the 18 and the 22.

Andy: I think Downs is 18.

Woman: Okay, so I've done the 22.

Woman: 18 is Downs I think, yeah.

Woman: What is PKU?

Andy: Phenylketonuria.

Woman: And that means?

Woman: Your baby is tested, when your baby is born, it's tested for this, and it's taken care of immediately. PKU kids usually, sometimes will be ID, they could be mentally, they are on a diet for the rest of their lives.

Woman: Phenylalanine, which is diet sodas and stuff, it'll say right on there.

Woman: They can have mental retardation, if they still use that term, ID I guess. Or they can be severely learning disabled, or they can do pretty well.

Woman: Okay, thank you.

Andy: Are you, do you currently have any children with any genetic or metabolic conditions in your classes now?

Woman: I have fragile X.

Andy: Fragile X? Any other ones?

Woman: I told you about William's syndrome, I've got a few kids with Williams.

Woman: I've got a lot, I've got quite a few Downs.

Andy: You have Down syndrome as well, okay.

Woman: Williams.

Woman: Fetal. Fetal alcohol.

Woman: Does Prader-Willi count too? Not that I have any, but...

Woman: Prader-Willi, yup.

Andy: Prader-Willi, yeah. So, I'd like to kind of switch to...

Woman: CP.

Andy: What are the concerns that you or the needs that you feel... What are the concerns that you have, the information that you need to have, the concerns you have about dealing with children with genetic or metabolic diseases in your classrooms? So, what are the concerns you have, or what are the...

Woman: I'd say for me personally, is as the students are getting older, and there is, and I say older, but they're only in like 3<sup>rd</sup> grade or whatever, it's the academic challenge. You get them to a spot of, and they're in the classroom, and the gen ed teacher looks to you as to have the answers, and they're already having an accommodated program, but even that, it's trying to continue to build their success, and finding appropriate alternative programs to make them successful.

Andy: So, it's the academic component of it, and how you deal with it.

Woman: And I think that reflects on their social, you know how they...

Woman: Yeah, I was just gonna say, social is a big, big, big key.

Woman: Especially as they get older, I can only imagine in middle school, because they understand that they are very different and that they learn differently.

Woman: And so, I was gonna say for me, you know a lot of the ground work has been done by the kindergarten and first grade special ed teacher, they've really worked hard at figuring them out. Figuring them out behaviorally and by the time, a lot of times when they come to me, they're in a better place and they're ready to academically learn, and then you feel very stuck about what type of a program or information is out there to best suit them and you feel sometimes that you are tied by the budget if you needed to go out and access the needed things

that you need to be able to plan for them effectively.

Andy: What about the medical information?

Woman: I was gonna say, medically I mean, things like allergies. You know, are these kids prone to certain, you know, allergies. You know, whether it be food or whether it be things in the environment or the other thing that I was thinking, are they prone to seizures? You know, are there certain diagnoses, you know kids are prone more to seizures or you know, different things like even things like, you know tremors, and those types of medical issues, which certainly impact their functioning in the structure of the classroom.

Woman: Like, Hunter's syndrome, I mean some syndromes you can have a progression, a downhill progression, rather than an uphill progression. And I think sometimes we have to acknowledge that and watch for it.

Woman: Right, and I mean in some kids their tone changes over the years, you know their muscle tone can decrease, their, you know which certainly is going impact on their feeding, on their, you know, and that's the type of information that as a clinician practicing within the school system it would be nice to be able to just go and you know, to be able to have that...

Woman: And also, if we had that information of expectations as far as anatomical and neurological expectations, that we can give parents sometimes. You know? Sometimes parents get stuck in, you know, "I want my kid as normal as possible", and sometimes that blocks a lot of progression for the student, you know, when you're trying to push the student more in the normal range rather than pushing them into an avenue where they succeed better and they feel better about themselves. So if we had more information, especially about neurological and genetic disabilities, then we can say, "Look, you know, this is what your child has, you know? These could be some of the expectations that you may have to deal with as he gets older, or she". But it think sometimes if we had some information that we could just pull down and even give to a parent.

Woman: Do you see this site as being a tool to be used for, okay, these are the potential conditions of this syndrome and this is how it could impact you as a learner or you as a you know, the child as a learner? Do you see that as...

Andy: I think absolutely. And I'll show you some of the ways we've got it mocked up now. The original goal of this, and I think... is for a classroom teacher, say a gen ed teacher, who you all have experience with this, you are trained in these areas, you are dealing with other special education teachers that have progressed with the child. Put yourself in the position of a gen ed teacher who has a child that comes into their classroom and they don't have the experience and background that you have. What would be the things that you would think kind of teacher would have, or what are the things that those teachers would ask you about a child with a particular disability or disorder?

Woman: A lot of times, at a low level, it's you know, what's the medical background, or what has happened up to this point, what should I expect, what's it gonna look like? Those kind of things, because a lot of them don't have any idea.

Woman: And they're fearful.

Woman: It's the whole uncertainty of not knowing.

Woman: What can I do, what can't I do?

Woman: Like how far do I push this child?

Woman: Strategies for when they...

Woman: Exactly, what do I do when they start to fall apart? I mean, am I pushing too hard?

Woman: Or is there is a reason, or, right.

Woman: Where you guys have the expertise a little bit more to know.

Woman: And I find a lot of people tend to be afraid of special needs students. I keep telling them, they're not breakable, you can still have them do this, let them try it. And I think just knowing that sometimes helps out.

Andy: What's your sense? You guys are all quiet over here.

Woman: Um, from a gen ed teacher point of view, I think those things that you mentioned and also even right down to dietary, you know, can they have these snacks, can they have that snacks, do I have to provide something different. And I noticed that in the flyer field trip checklist, that's a real area of fear, is taking a child with a condition you know outside of the school boundaries where there may be some security and sense of familiarity, what do we do with the child on a field trip? Can they even come? Those kinds of things.

Andy: Um, any other things that you?

Woman: Yeah, I just think along with that whole fear thing, if there is an IA that's assigned to the child, sometimes the classroom teacher becomes so dependent on that IA taking care of that child, that they can really detach themselves from it, and I sometimes think that there is, you know, I see that, I think it happens a lot.

Woman: Mmhm. It happens a lot.

Andy: Mmhm. Um, let's change gears a little bit. Where do you, if you needed information about a particular medical condition or any special implications that you would have for assisting children with this, where do you get it now?

Woman: Internet.

Woman: Google.

Woman: Google, absolutely.

Andy: The internet? Really?

Woman: Pediatrician.

Andy: Pediatrician?

Woman: I have books from college and stuff about development and different kinds of syndromes and things like that, but, I usually Google.

Woman: More so the Google it, you know.

Andy: What do you think is the best way to get information about educating students with genetic disorders. Is it through, you mentioned websites, the internet, brochures, posters...

Woman: I usually think of the internet as like the first, and then if this is a certain style that fits with that, then I might go onto like Amazon and purchase the books so I can read up more about it and how best to go about implementing a plan.

Woman: Colleagues.

Andy: From peers? Peers and colleagues.

Woman: And to go even like, like you said, right to the physician, I mean sometimes we'll go right to the physician and the physician can send out information or whatever.

Andy: Right, right. Any other places that you know, would be the best way to get information?

Woman: Lots of times I talk to their actual physician, they are very willing to talk to you about their needs, and the parents.

Woman: The parents.

Woman: The parents are well educated on what their kids need.

Andy: Sure. Um, if you had to think of the kind of information that would be important to you and your roles or, and also I'll ask this of the gen ed teachers who don't have the backgrounds that you do, what do you think is more important, practical knowledge about the students with these disorders in the classroom, or more specific information about the genetic basis of the disorders? How to deal with it, or what is it and why does it occur.

Woman: I want both.

Woman: Yeah, but a classroom teacher?

Woman: Classrooms teachers, they want to know the practical.

Woman: How to do all that, yeah. They don't care about all that other stuff.

Woman: I think we want to know both.

Andy: So, you would be more interested in having more richer detail about the causes and some of the implications of that, but a classroom teacher?

Woman: I don't know if that's fair to the classroom teachers. I mean I think they would...

Woman: Yeah, a lot of them ask me about...

Woman: Well, I was a classroom teacher for 4 years. I would want both though.

Woman: You know, that they would definitely benefit. Right. I mean, I would think that's really an individual, and I mean there are many classroom teachers out there that I think would want both.

Woman: Want to understand it.

Woman: But they want to understand it first, and then maybe as they get to know the child a little bit more, then they want more information.

Woman: Right.

Woman: My experience is the opposite. The team that I work with, you know, I can say would want to know first the practical how to's, and then you know, if they get to learn along the way about the syndrome, that's just my experience.

Woman: Basically they want to know how to deal with it.

Woman: In the younger grades, I think we have more of a leeway of getting to know them, and letting them kind of adapt to school.

Woman: True.

Woman: Especially in Kindergarten. Letting them get used to our, before we have to deal with...how do we help them to learn.

Woman: As the rest of the kids are getting used to it.

Woman: Exactly. Everybody kind of starts at the same spot, but in fourth grade, it's a different situation.

Andy: Yeah, so imagine that you have a child that comes in fifth grade. He is new to the school district, you don't know him, and he's got a particular IEP that he comes in with. You're a teacher. What do you want to know? The more practical information about what happens, or?

Woman: Right, because I think at that point, it's the survival of the new student and the gen ed teacher. You know, you want to make them most comfortable, feeling adjusted the quickest for both student and teacher. And then once they feel comfortable, then they can kind of learn more of the background, if they are coming in, especially if they are coming in mid-year. That's really hard when programs are up and running and a class has clicked, and then you have a new student come in, so you don't want to put them at any more of a disadvantage besides being the new

student. You know what I mean? So.

Andy: Right.

Woman: Well, you're talking about a teacher, but in this grade level, there might be 4 or 5 teachers in a day. So they're only gonna see them for 45 minutes, they want to know, quickly show me what strategies work and what I need to know about this kid, and that's what they...

Andy: Do you see, do you really see that difference from the advanced grades? I mean, put yourself in a high school teacher's mind.

Woman: Same idea.

Woman: I always call it a different monster. Because I go from 3-21. I follow the kids from preschool all the way up, because I'm the only therapist. And every, I see the parents panic, from Good Year to KCS or KMS, and then they get used to that school, and then they have to come up here, the whole ball game changes, right? And then when they go from 8<sup>th</sup> grade to high school, then everything changes again, and you know, it's scary for the parents.

Andy: Yeah. We just, we go from fifth grade, which is still like continued of elementary school, to sixth grade this year, which is a lot of fun. Well, what I'm gonna do now, is I'm gonna walk through this. And what this is, this is a mock up version of it. This is just on power point, so this is not the web version. We want to make sure we have the concept right before we send it out for the web monkeys to do all the design of it. So, um, and it's being developed to provide information about children's specifically with genetic or metabolic disorders, but what we're hoping to be able to do is build a platform that is scalable to other conditions as well, so autism, some other things that the classroom teachers are gonna have to deal with. And it's designed from teachers first of all, but we're also thinking that this would be something helpful to parents. A resource for parents, if only to cue a teacher as to what to pay attention to in the classroom, and we have also talked about expanding this to pediatricians because frankly, even though they're the doctors on this stuff, you'd be surprised at how little they understand about the practical implications.

Woman: We're not surprised!

Andy: Okay, I was trying to be polite.

Woman: You don't have to be.

Andy: So, let me walk through and just kind of show you how it works, and it'll look fancier than this on the front screen, but basically on the front screen, we're conceiving having a list in a drop down fashion of various disorders. And you can choose which one. We're also talking about having it at different ages, so it's kind of age appropriate. This is like first grade or under, elementary school, middle school, high school.

Woman: That would be good.

Andy: So, because kids have different issues and different things at different ages. So, there's a lot more to it than what you're seeing here. The other thing that we really want to expand it to is

if you're a parent, these are the things that you need to pay attention to, if you're a teacher, if you're a pediatrician. So you have to kind of squint your eyes a little bit about what we hope to do. So, it would have the list of options, and you'd click on one of the options, and it would take you to a screen something like this. And this was designed purposely with the child in the center, and all of these different things around them, because all of these different areas impact this child's education. So we've got educational supports, what is this particular disease, emergency plan, fatigability, dietary issues, absences, behavioral supports, sensory supports, other conditions if they decline, if the condition declines or changes, and special trips and functions. So some of the things you've been talking about. And the way it would work, is you know, you'd click on, "What is PKU", and it brings up in as plain a language as possible, and we've got a staff of people that are working on the text in these areas to make it informative and accurate, but also easy to understand, quick to understand. And then there'll be links that will show up of places to get more information about this. This NIH, this NCBI, I forget what that stands for, but it's a big online, if you think about glossary, but it's like a...

Woman: Like a data base?

Andy: A big data base of all sorts of conditions and factors on it, so it'll have that kind of information. So, this is the generic, "What is it?". If you want to have an emergency plan for this child, for PKU, they say there's really no particular need in this area for an emergency plan, and again, this is all embedded with the, it's accurate information. So, there's some things about fatigability, not a particular problem for this issue. "Dietary Differences", yeah, all of the sudden you have a number of, uh, you need a low protein, low phenylalanine diet, and it goes through specific things that you would want to have. Access to a refrigerator for special formula, allow the child to have access to a refrigerator or a microwave, because they probably know more about their diet and what they need to do than you do, especially if they're in third or fourth or fifth grade something in that range. Involve the parents to make sure that on special days the student has an appropriate treat for them if that's allowable, involve the parents in bringing food in, make sure that the school nurse is hooked into it, a lot these things would happen anyway, but these are the practical things that a teacher would need to know. I should say, these are not complete lists yet, but this would be the kinds of information, the practical information for teachers. And preventing sharing of food. Are there any increased absences to this one? Not particularly, it's not a particular issue for PKU. Are there any behavioral supports that you would need for this? Sensory supports, not really. Maybe this is not a...the condition declines or changes, it tells you what to watch, watch for new or different learning needs and they indicated change in phenylalanine levels. Watch for changes in puberty or other kinds of rapid growth or high energy expenditure. Phenylalanine levels are affected by even minor illnesses, so some of the practical things the teacher would be able to pay attention to, so if you see a child who is really getting worn down over a couple of days, you might say that there's some dietary things you may need to pay attention to or be aware of. And so, it involves you metabolically when questions arise about the condition or changes in the child. I'd like to just go around the circle here, mentions trips and special functions, will need special foods to take on a trip and make sure you involve the parent here, transportation of the special formula, you'd have to have that with you and somebody's got to be available for that. Talk to the volunteers, if you have volunteers, who is going to be responsible for what, and make sure that you have supervision around new eating situations, because you know, kids will be kids, they'll eat whatever they can, if something looks good, they're gonna grab the French fries or the hot dogs off the kid's plate even though they're not supposed to. If there are any specialized education support services, so this says consider developing a 504 plan, setting to include special

arrangements for lunch and for drinking formula during school day, executive functioning and activity levels are affected by phenylalanine levels. So this is information about PKU. And I've got a couple other examples of this, so if we go back to the beginning, Q22 deletion syndrome is another one. You asked me what it was, I don't know, but we can find out from here.

Woman: Let's find out. I'm pretty excited.

Andy: So what is Q22 deletion? The same sort of formula, where you've got the child in the center, and you've got all of these different things that may or may not be a concern for that child. It's DeGeorge?

Woman: DeGeorge.

Andy: It's a microdeletion of chromosome 22, affected children can have speech problems, learning problems, heart defects, problem with calcium regulation, immune function, again, more items and places to learn information about it. An emergency plan? Not particularly needed for this. Is there any easy fatigability? Check with parents to understand if there is any cardiac defects that may be of concern. Low muscle tone in infancy is common and may continue into early childhood. Older children are often clumsy and have problems with coordination. So these are things that you would pay attention to if you were seeing this in a classroom. Are there any dietary differences? Not really with this one. Will there be any increased absences? Yes, you can expect that, young children may be more susceptible to infections because of immune deficiencies. And then there's other causes, surgery, multiple specialist appointments, etc. So this would be a concern with absences, it would be something you'd have to plan in to this child's education plan. Any behavioral supports? It says 30-50% meet the criteria for ADHD, medication may be appropriate. Sensory integration programs are important to help with self regulation, 20% will have a psychiatric diagnosis as adults, anxiety disorders are very common. So information about what to expect with behavior for this child and how you deal with some of the basics, to put together a behavioral plan. Again, this is designed more for classroom teachers, if you are in special ed, you would have more of this information, and more of a background. This was designed to be practical information for the classroom teacher. Again, sensory supports, sensory integration problems, generally no issues with pain. No particular concerns about decline of the condition in this area. Any problems with special functions or trips? No, not really. And then, are there any specialized education support services, and here we'd have a number of things that are general supports. Consider an IEP as learning problems are common, talking about some of the issues here, poor executive function, having to break larger problems into steps, and some things like this in dealing with the child generally, but then there's speech issues.

Woman: Can you click on math?

Andy: Which one did you want?

Woman: Math.

Andy: Math. They have issues here. This is an area of most pronounced learning deficits, visual spatial learning difficulties, etc. They're focusing on number sets first, then repetition and practice.

Woman: I'd like to see the fine motor.

Woman: You would!

Andy: I like that you're interested and wanting to get information, this is hopefully what...

Woman: I want to see what that looks like.

Woman: Now, I'm wondering if there's been studies on so much of these children over the years and in school, like a part of that, okay, so you click on fine motor, and then out of that, maybe programs that have shown success?

Andy: Okay, so that's a good point. So if we could have some specific things in here that they could look at on this page for more information of the specific suggestions.

Woman: Right, to put some either links or whatever, that would, some tools that they could benefit?

Woman: Because, you know, I looked under what the math was the telling of time and money skills, you know, I'm sure it's a multisensory approach, you know, but little things like that or programs that really focus on that, kind of like a tier underneath that, that would be, even the classroom teacher...would be good information.

Andy: Okay, good. Then some of the other things, reading skills.

Woman: Even if there was a part of this where teachers could write in, you know...

Woman: Oh, like a blog?

Woman: Yeah, I've used the...

Andy: Like suggestions, a place where they could put feedback back into it.

Woman: Yeah, "This worked great with this child, you may want to try this program". You know?

Woman: And I know this is a lot of work, but like, a mountain needs a well structured reading program with emphasis on explicit building of comprehension, like what? What are some...

Andy: Specific examples of what to do, programs to use.

Woman: Or what comprehension strategies work out best with this particular type of child.

Andy: So you're saying that you'd like even more detail than the kind of information that's on there.

Woman: Because I think this is very good, but it gives you a very general, but okay, so now I know all this stuff, so what do I do with it?

Woman: And not that it even has to show at this point, but that you could access it from this point.

Woman: Right.

Woman: Because you know, too much is not good on a page either, so.

Woman: Because I do like the simplicity of this, somebody who is not into, like a teacher, can just go quickly on this, and just kind of get an idea of where this child is, but I think you know, like she said...

Andy: You'd still like the extra? The extra information, the extra links.

Woman: You can go into more depth.

Woman: Right, because it would make it, right, more user friendly, and...

Woman: And just to have other people write in as to what programs work and how they like it and how they don't.

Andy: Just some more of the information that's on there. So, more detailed information would be helpful. And let me go through the one other one that we've got mocked up here, is for sickle cell. So, "What is sickle cell disease?" Red blood cells, the blood cells become hard and pointed instead of soft and round, painful, mild to severe. Specifics about it, and then more information about the disease.

Woman: Yeah, just like you have the links on that one.

Andy: Mhm, but in those, I gotcha. "Is there an emergency plan?" Yeah, for this one you do need an emergency plan. Pain crises are the main reasons why children go to the emergency room and get admitted to the hospital. Dehydration, what to do, call the doctor. "Fatigability", normal classroom activities shouldn't, but if you do exercise or so forth it becomes difficult.

Woman: I'm wondering if there shouldn't be some discussion of visual someplace, you know what I'm saying?

Andy: As one of these major areas?

Woman: As one of those, yeah. I'm just wondering. Because some of these metabolic issues certainly affect vision and I don't know whether it would be...

Woman: Oh, like cueing?

Andy: Maybe instead of like sensory supports, supports for pain, more of you're thinking of just what to expect about their...

Woman: Well, visually, sometimes you know, there are certain diagnoses that the vision is definitely more prone to be affected, so I'm just wondering if that, because that's such a big impact now a days.

Andy: I'm thinking of my son with autism, sounds are really hard for him...

Woman: Hearing, vision. Right, all of that.

Andy: Any sort of noise or that sort of stuff.

Woman: So, maybe that sensory supports or supports for pain need to be...

Andy: There'd be some information about that.

Woman: Needs to be relabeled.

Andy: Okay. Okay. So this has, let's go to specialized educational supports, no particular needs in this area, so this is kind of the mock up of the idea. I hope you get kind of a sense of it after hearing the discussions, "yeah, I'd like some of this, and more of that", I think you kind of get an idea of what we're trying to do. So let me just ask some general questions. If this gets done in its bells and whistles, would you think that this would be something that would be useful in a classroom setting?

Woman: I have a question. How much does this cost, or is this gonna be free to the teachers?

Andy: It would be free to the teachers.

Woman: Oh, it's a great program!

Andy: It'll be on the web, so you just, it'll be available really to anybody.

Woman: I think it would be helpful. It's certainly better than what we have now, which is nothing, or us.

Woman: Right. And I think the set up, I think that the way you've got it set up is certainly...

Woman: It's user friendly.

Woman: It's very user friendly, and I think you know, to just access the information they want quickly and draw from it very nicely.

Woman: And I like that they don't have to see it all at once, that they can choose a particular piece.

Woman: So, if you can only handle so much, you'd go there once a week. You could look at one.

Woman: We're going on a field trip, let's see what we need to do for my child for a field trip.

Woman: Yup, exactly.

Woman: They don't have to study it and memorize it, it's very simple. I like the simplicity of it.

Andy: That's kind of, that was our big goal, was to make it as informative without being overwhelming. And when we were originally were putting this together, it was going to be like a poster, and we said there's no way you can do this, you can't put this in one, put it on a website and you can be able to get this background information and let the user drive, their own need for the information drive how far down they go into it. What do you like least about it? What do you think is the biggest problem? You mentioned a need for more additional information.

Woman: The colors.

Andy: The colors, alright. Well, this is why we...

Woman: I don't mind the colors.

Andy: We've got the web monkeys for this. It will certainly look more finished than this. This is what you can do with power point.

Woman: I think it's a great program. I think, you know, even the way it's set up, it's not confusing, it's not overwhelming if a parent or a teacher gets on there, it's not overwhelming. Do you find it overwhelming?

Woman: No. You're looking right at me, like I'm the one that doesn't have a clue about most of this stuff, so absolutely, I think it's good. But I really think that you need that link for the parent that's more interested, the teacher that wants to know more.

Andy: Mhm, you'd like those different.

Woman: And the special ed teacher who already probably knows most of that stuff, but wants more.

Andy: In fact, one of the things that would be helpful I think for the design part of it, the special ed teacher might be able to bypass some of the easy information and go to the more in depth information, the detailed information about where to find things.

Woman: And I think even like dietary differences, you know, suggestions for the classroom teacher, especially the elementary, because there is a lot of food that goes through a classroom in the elementary.

Woman: And there's a lot of snacks that the teachers bring in.

Woman: Right, for the kids.

Woman: Or other parents bring them in.

Woman: So, my other point is, yeah, I'm thinking how I'm gonna...say if you would want...

Woman: Karen! This is Karen talking!

Andy: Alright, no names.

Woman: Alright, say if you would want to print a portion of this, so that you could attach it to the child's folder or something, so to make it user friendly that way, so okay, I need dietary information on this kid and I need it someplace so I, to incorporate that.

Andy: We've already, we've built it so it would pop up a PD app so you can print a PD app, save it, do whatever you'd like.

Woman: Excellent, so that's good.

Woman: Okay. Now I'm not sure if it would go in another spot, but something for accommodations or modifications that may be necessary in the classroom?

Andy: Accommodations in the classroom? So, another, like a button there. I think with the specialized education support services...

Woman: It might be in there.

Andy: Maybe a button that says classroom accommodations.

Woman: Because that's what the regular ed teacher wants to know, how do I have to accommodate this child.

Woman: I think it's good as a parent. Because I know when a parent has like, I can remember, I mean my son is 18 so, I can remember going into a PPT when he was in kindergarten or first grade, but if a parent goes on it the night before and uses that as their checklist for their PPT, you could go in and make your own notes. Because you're going in as a parent and there's 12 people sitting around the table, and it's you and your husband or you, and you can use that as your checklist and say, "Okay, I would like to talk about, you know, Jeremy's emergency plan. I'd like to talk about Jeremy, how he is when he gets tired. I'd like to talk about, you know, Jeremy and his dietary", and then you kind of control the PPT and then you kind of almost feel better. So I think it can be used as a great tool as a parent, because the night before, sometimes like, I know as, I mean now he's 18, so I'm kind of like this with his PPT, I could you know go pretty well with that, but.

Woman: You could do it in your sleep.

Woman: But as a new parent, this is great. Because then you yourself can explain, "My child has sickle cell, and this is sickle cell disease".

Andy: And this is what you have to make sure that we include.

Woman: And this is what it is. And sometimes it's more comfortable as a parent.

Woman: It gives the parent the right to integrate...

Woman: Then it gets the parent running the meeting instead of the special ed teacher running the meeting. Then the parents running the meeting, and then it's almost more relaxed I think. I

think it can bring it a little, you know, I think it would work better for the parent, the parent is not just sitting there and saying, “Hey, Jeremy’s doing great”, and you know, I think it would be a great learning tool for a parent.

Woman: That’s a great point.

Andy: That’s good. Good. That’s...

Woman: You know, I think the other thing too, as a person sitting across the table at a PPT, that’s great, because it gives you something to work off of. “Oh yeah, that’s a good idea, yeah, well, you know, I think we need to do that”. And it’s kind of like you’re working together with the parents.

Woman: It brings it back to a team philosophy.

Woman: It does. It brings it back to the team instead of I’m sitting here and there’s 12 people there, you know?

Woman: Or using initials that you don’t know what they mean.

Woman: Exactly. Like you said, you’re breaking it down into the simplest terms so it puts everybody on the same playing field. I think it’s great.

Woman: And you can use that as a guidance to writing your goals. You know?

Woman: Sure.

Woman: Well, I was thinking about the accommodations page, when you’re sitting in a meeting. You may have to, if you didn’t have this information, you may have to say, I’ll have to check that, we’ll see, you know in terms of dietary for example. You know, you might not be able to complete that at the meeting. You may have to come back to the table to add information that you wouldn’t have had.

Woman: Wouldn’t it be great if you, even if you had something like this and you had a child that had sickle cell and you knew that. You had a PPT, if you could utilize something like this right in the PPT also.

Woman: But in your marketing of it, you would almost need to state that, you know, this could be used as an assistance for developing an IEP within the PPT forum. So I mean, you really almost have to bring it to, you know, have a whole plan or how they could use this tool.

Woman: I think it’s great for teachers, but I think you should approach it to the parents too, because I think it’s great for parents.

Woman: What about, and speaking of that, why not having something about um, birth to three services in there? Because I mean, that’s really when you feel...

Woman: 0 to 3...

Woman: I'm sorry, I know you're trying...

Andy: No, the practical answer is the original grant that was developed for this, was to focus on elementary education, but I think your points are absolutely the case, is one of the things that we saw, you know the difference between a child that's in a kindergarten classroom vs. a child that's in 6<sup>th</sup> or 7<sup>th</sup> grade.

Woman: Or early intervention.

Andy: There's a huge difference.

Woman: Right. Because you need a social piece.

Woman: But maybe instead of birth to three, how about elementary focused programs. Other outside programs people can...

Andy: So, you mentioned social?

Woman: Yeah, I think there should be a social button.

Andy: Like a button there for social? Yup.

Woman: Because you know, some of these kids you know, you could say, "Okay, this child has sickle cell, he may have difficulties interacting with other children and he may need extra accommodation to understand facial features", or whatever you want to put in it, but I think the social piece is so important for all our kids nowadays, and I think that needs to be a button.

Andy: Okay. That's good.

Woman: It's almost like you could use it as your questionnaire, you know how like they always send out the PPT is coming...

Woman: Maybe it could be behavioral/social.

Woman: The yellow piece of paper?

Woman: You know, this, this, this. If you sent this out, "Go to [www.this](http://www.this)", and have the parents fill this out before they come, it's almost, or "Look at this before you come".

Andy: So, like a parent checklist.

Woman: It's like your parent checklist. It's quick, it's easy.

Woman: You could at least offer it.

Woman: You offer it. I mean.

Andy: What other things could be done to improve what you're seeing here, other than you know, like the color?

Woman: The button.

Andy: Well, the buttons will be...

Woman: The social button.

Andy: The social button, I think that's a very important one to have on there. And you've mentioned some other ones, some of the, kind of the senses, the sensory challenges.

Woman: The vision. I think some of the other, right. Right.

Woman: How about like their family background?

Woman: Yeah, that's what I was gonna say.

Woman: Like their family background, like they have like this disease, but you may not know, like I know with Jeremy, he has a sister, and he some days, you know if he's not getting along with his sister, he's not gonna have a good day, or he may have gotten into an argument with Dad. So you may want to have a family history, you know.

Andy: So, other things to be aware of.

Woman: Think about, this is a tool that...

Woman: Or an other button, or...

Andy: I think that what you're looking at there, is if we have a specific tool for parents, which I think there is definitely a desire to do that, that would be a point there that would be very important for parents. Not as important for school teachers, for teachers in the classrooms.

Woman: So maybe that could also become another little box there, just parent supports.

Woman: Yup, parent supports. Where there are links on that parent support that you can go to. That you know, if your child has sickle cell, go to this and this is a whole bunch of parents that talk about their problems.

Woman: Now, I have a question, would I select this because it says teacher a child with sickle cell, did I get that because I clicked on teacher?

Andy: Their original, the one that's gonna come out first is going to be designed for teachers because that was the grant, was design something for classroom teachers, but what we're trying to do is build something and say you know, if we could build this for teachers, let's think more broadly now and be able to scale it to other populations, parents, healthcare professionals, pediatricians, whoever...uh, maybe special pages for just special education teachers or experts in these areas, and then by age category, etc. So, we want to be able to make it as scalable as possible down the road. Initially, it's going to look like this, with teachers. But our goal is to make it much more broad.

Woman: So, then when the parent clicks on it, it will be something like parenting a child with sickle cell?

Andy: Right. You click, "I'm a Parent", and I want to know what, and that might be actually helpful if we get to that level, if you're a teacher, would it be helpful for you to have information about what parents ought to be doing or ought to be thinking about for that child as well.

Woman: Parent suggestions. Social, then parent suggestions, um you know to follow through working with the school system. Parent and teacher working together could be a block.

Woman: And I'm thinking too, as part of the specialized education support services a question that general ed teachers have, is "How do I assess, do I assess differently because this child has this condition?" So maybe you know...

Woman: That could be under the accommodations or modifications button.

Andy: Accommodations and modifications button. That would be good to have under that specialized education support services. Yup.

Woman: Well, I think it needs to be another button. Well, you can't put too many buttons...

Woman: I like buttons.

Woman: I love buttons. I like to click.

Woman: What about in regards to, like, their generalized, like ADL functioning. Meaning activities of daily living, meaning you know, do we need to put something like that for the classroom teacher? Would that be included in any one of those buttons already? I'm not so sure it would be.

Woman: Well, maybe under...

Woman: Like how does a child, you know, are these children have a tendency to you know, have more accidents, or are they gonna feed, I'm just wondering.

Andy: Right. I think that maybe that's something in the behavioral supports or concerns there.

Woman: The behavioral supports is how you're seeing that?

Woman: Socialization could be under the behavioral.

Woman: Specialized education support services, I mean you might have ADL skills underneath that.

Woman: Under where?

Woman: Specialized education support services?

Woman: Toileting, dressing...

Woman: That type of information would be important to the classroom teacher if there were special needs in those areas. So maybe looking at an ALD checklist and you know, just kind of having somebody go through. You know? And incorporate that information into these different diagnoses.

Andy: Mmhm.

Woman: It could be how they present. It could be under what is sickle cell disease. How do they present in the classroom? Could have toileting problems, could have whatever down the line. Right? If you wanted to get into something.

Andy: No, I think it's important to have that kind of information someplace.

Woman: I think that's, how do they present and how should I treat them. Accommodations, modifications. That's what they want to know.

Andy: Who do you think should have access to this kind of a tool?

Woman: Anybody who is interested.

Andy: Anybody who's interested?

Woman: Yeah, absolutely.

Woman: We should have access.

Woman: Anybody who works in a, I mean anybody.

Woman: Aides, I aides, even custodians.

Woman: Anybody that really, you know, is interested.

Woman: I would think this would be super helpful for, especially if you were an instructional assistant working with someone or even as a teacher, anybody working with a student you've never had before, that would be very helpful.

Woman: Specialty teachers always say, "I have no information".

Andy: If you were in a classroom, how often do you think you would use a tool like this?

Woman: As often as you needed it.

Woman: Every time you get a child with a new diagnosis.

Woman: But I also think it depends on the child and the child's level of being able to function in the classroom, and you know you might go and an be like, "Oh my God, we have a field trip", and you might check it then, and then you know, the child starts to, you notice that they're getting tired. You know that this is available, do you know what I mean? So I think it really

depends.

Andy: It depends on the child.

Woman: Yeah, I think it depends on the child.

Woman: And I think it depends on how comfortable people are with the tool. You know, you make it user friendly enough, people are going to be comfortable with it so that they know that they can...

Andy: That's what the web designers are there for. They know how to do it.

Woman: Yeah.

Woman: That's what the geeks do.

Andy: Um, if you think of, put yourself again in the head of a general education teacher, how often do you think they would use it if they had a child in their classroom?

Woman: Well, I think some teachers probably a real lot, and to be honest, there are some teachers that probably would never get on it.

Woman: Probably more towards the beginning of the year?

Woman: I was gonna say, initial onset, your initial onset of these conditions.

Woman: And before a PPT. So I can affirm a gen ed person's point of view. I'd say probably three or four times a year. Before report cards, before, you know or when you're making sure you've assessed everything for a report card, I could see it.

Woman: Development of goals.

Woman: Where they have to talk to parents at report card time, they would be a lot more intelligent talking to the parents.

Woman: So, like 4-6 times a year, I would say on average, but it also depends on how involved.

Andy: From a parent's, you mentioned from a parent's perspective, how often do you think you would make use of something like this if it were available?

Woman: Probably before PPT's, parent teacher conferences,

Andy: Probably a lot more when your child is younger than older. Yup.

Woman: Or as changes happen, because puberty changes everything.

Woman: Or you know, you recommend it to new parents, and you help new parents and you hear new grades.

Woman: I'm thinking some of this information is gonna remain static, I mean, what is the disease, is gonna stay the same, but as we improve our, even our technology with working with kids in these areas, some of that information will change as we go.

Andy: Yeah, that's one of the things that we see that if this gets scaled to a larger scale, there's gonna have to be kind of regular updating and improving, and adding additional information on it, and I think earlier somebody had mentioned about having kind of a feedback loop where teachers could suggest or parents could suggest things back.

Woman: I think that'll always change.

Woman: Which will affect the access.

Andy: Maybe there's even a, it would be helpful to have like a forum link on this. That would be helpful.

Woman: Guest speakers could come in. Podcast it, there you go.

Andy: Is there anything else from what we've shown you or anything else you feel that we haven't touched on? Or that you think would be important to have or change or to think about that we haven't discussed?

Woman: Possible special equipment for classrooms.

Andy: Special equipment? Okay.

Woman: You know, It'd be kind of nice if they could kind of click onto...

Andy: That'd probably be under the special education support services, but I think...

Woman: I'd like to see something like if teachers are going to have a child, okay, a child's coming in CP, they look at their IEP, okay, and they're gonna have a Rifton chair, and they're gonna have a side lyer, and they're gonna have a prone stander, you know, a way where they could...

Woman: I would want to know what those things meant.

Woman: Right. A way they could click on and have it go to a website with pictures to see how big this equipment is and how I have to set up my classroom, "Oh my God, I've got all this stuff coming in, what am I gonna do?"

Woman: It's big.

Woman: And I think...

Woman: I'm always dumping in her classroom.

Woman: But I think, you know, if especially if you do a heavy duty child, that is physically

handicapped. You know, I think if you had access or some way for teachers to be able to go into the equipment realm and see what they are gonna have to be dealing with with kids.

Woman: I mean you could put Rifton, and all the big companies right on, so that they can just put in “prone stander”.

Woman: Teachers will need to know how to set up their room to accommodate that student.

Woman: Right. The equipment.

Andy: Any other things? If you do need any other things, we’ll leave a card so you can get in touch with me, because we’d be happy to include anything that we can with this. But that’s all the questions that I’ve got. I want to thank you all for coming and helping us out and providing the feedback. This is very helpful because we can think of some of this, but we’re not in the classroom.

Woman: How many different states are you?

Andy: We’re gonna be looking at I think 6 different places and urban/rural, places with more resources or less resources. So...

Woman: I think we fall under the less resources.

Woman: And rural.

Andy: I think every school thinks they’re in the less resources. But, we’re looking at a number of different places across all of New England. So...

Woman: This is really, really nice. I think it’s a great idea.

Woman: It’s a great tool.

Woman: It will be a big help.

Andy: One other thing I didn’t ask about, what do you think would be the best way to inform people about this? To inform teachers or classrooms?

Woman: I think you should role it out to people services directors.

Woman: Special ed teachers.

Woman: To pass right to teachers.

Woman: What to they call it, the meeting of the special ed directors.

Woman: Special ed directors, what Concave or whatever, your state special ed bureau office or whatever.

Andy: Statewide. Yup.

Woman: I would present it to them. I wouldn't email it to them, I would present it to them and then let them take it back to their schools. Because best thing is word of mouth.

Andy: And again, we're, because it's gonna be on the web. It'll be public access to it.

Woman: Well, it, you know, think back for a second, if you're actually going through, you're looking for that gen ed, you keep bringing that up a lot, you know, then it's not your special ed, you know what I mean? It's your department event or.

Woman: But let's think about it though. If you knew about it, and you had a child in my classroom, you're gonna tell me about it.

Woman: Right, but you almost want to overdo it, you want to go in through the special ed and the regular ed.

Woman: And the regular ed, I mean to principals to work it through that way.

Andy: Principals and superintendants hold conferences as well. Yup.

Woman: It could be part of your special ed meetings too.

Woman: And I think right now there is a lot of training going on with the SRBI, you know, if you got hooked up with some of the training, you know? And just, with the regular ed getting the training, you could just kind of do a little spiel with that. This is a great way of SRBI.

Woman: Yeah, and that's a big thing. I mean, you could set this up as a real good SRBI intervention tool, and everybody's jumping on those now. I mean that's the big push.

Woman: Buzzwords.

Andy: Before you leave, Tracy's got something for you.

Woman: Okay.

Andy: Any other, are there any other things that we haven't touched base on?

Woman: You said all the genetic disorders to start with.

Andy: Yup. It's gonna be starting with genetic disorders. If you think of non-genetic disorders, autism is certainly one they've been talking about, autism spectrum disorders. Any other um?

Woman: We just got a little boy at Good Year, and he has Weeping Capillary Syndrome.

Woman: Wow. That's very rare isn't it?

Woman: Very rare. There's only 24 cases that have been studied that are adults I think in the US. And there are only 3 or 4 children, he's one of them.

Andy: Wow. And I think that points out some of the issues that you've got with this. There are

so many metabolic or genetic diseases to expand to. I think they'll be tackling them in order of prevalence. So...

Woman: And I think a lot of these genetic diseases are very scary for people who are dealing with these kids. I mean, when you talk about a Weeping Capillary Syndrome, it's like, "Oh, do I touch him, will he start to bleed internally?" You know, and it's really not like that. It has more to do with like getting, like cold symptoms and stuff like that. But I think it'll take a lot of fear out of people that are dealing with these kiddos.

Andy: Good. Alright, that's it. Thank you! Now we do have one last thing, you gotta bring food and cookies and stuff home with you. And Tracy's got some gift certificates for you to use. We appreciate your time for coming. Thank you very much.

SMALL TALK

## Somersworth

Andy: I want to thank you all for coming and I want to get started, because I know you guys want to get on to your step class. My name is Andy Smith, I'm the director of the University of New Hampshire Survey Center and a political science professor and I want to thank you all for coming to this group. I'll give you a little bit of background about this. We are working with the UNH Institute on Disability and an organization called the New England Genetics Collaborative, and part of this, they've been working on a grant to develop a way of giving information about genetically based diseases to school teachers to be able to use in your classroom so you'll have a resource to understand how to deal with how to help children, what particular needs that children would have with these diseases. And what we're trying to do is we're going to be conducting 5 or 6 focus groups across New England with school teachers and paraprofessionals about what they're seeing in their classrooms, where they're currently getting information, and I wanted to kind of, we'll go through a mockup of this web tool that we've got. What we really want to do is get your feedback and try to make this even more usable, more user friendly, or informative tool for teachers or people that are in the classrooms with kids. So, have any of you ever been in focus groups, a focus group before? We've all heard about them. Basically, all a focus group is, is a you know, group like this, where you have a dozen or so people, and it's an open dialog group, open process. What we'd like to do is get your input as much as possible on these issues. I'll go, I have a moderators guide that goes through the specific issues and sometimes I'll ask you specific questions, sometimes I'll ask specific people who aren't talking so much to get their input, so don't be shy, don't be afraid. Um, there are no right or wrong answers. As honest as you can be would be the most helpful. I don't think we're going to be asking about anything sensitive or anything in here, but we are audio taping this, but that's just so we can have a record of what was said so, we can't write notes fast enough to keep up with all of this. Um, Tracy Fowler who you have met, she is helping out, she'll be taking notes for us as well. What I'd like to do is start off if I could just go around the room and if you could tell me just your first name and what your position is, and how long you've been in education.

Ginger: My name is Ginger, I teach a multiage classroom, 3/4, and this is my thirty-fifth year.

Andy: A rookie.

Melissa: My name is Melissa, I'm also a multiage, 3/4, and this is my third year.

Julie: And I'm Julie, I'm a speech language pathologist, and this is my seventh year.

Beth: I'm Beth, I'm a special ed teacher, grades 1/2, and this is my fourth year.

Holly: I'm Holly, I teach a multiage first and second grade, and this is my sixth year.

Angela: I'm Angela, I'm a kindergarten teacher and this is my twelfth year.

Laura: I'm Laura, I'm a special ed teacher, I work with grades K-4, and this is my second year.

Kathy: I'm Kathy, and I'm a paraprofessional and I'm working this year with the second grade,

one on one.

Marta: I'm Marta, and I'm an occupational therapist, and I've been here 6 years.

Nikki: I'm Nikki, I'm a fourth grade teacher, and I've been here for three years.

Missy: And I'm Missy, and I'm a fourth grade teacher as well, and I've been here 11 years.

Andy: Great, I'm glad we've got a nice mixture of people with different positions, this is really going to be helpful, hopefully for us. We know it will be helpful for you, this tool I think will be. So, let me go through some of the specific questions. I'd just like to begin by asking your experiences that you've had with children with genetic or metabolic disorders, some of the ones we might think of are PKU, Q22 deletion, sickle cell anemia, genetic and metabolic disorders. I know that a lot of you are having issues w/ kids with ASD, autism spectrum, but that's really not what we're speaking of here. I know that there are some genetic causes for autism, and it's a big issue, but this particular collaborative is focusing just on genetic and metabolic issues. So, what are your experiences that you've had, have you had any children with any of, either genetic or metabolic diseases in your classrooms?

Woman: I have.

Andy: You have?

Woman: Last year I had a little girl who has, I don't think it's 22Q deletion, but it is...

Woman: No, it was like 11.2 or something like that.

Woman: Yeah, some sort of a deletion of a chromosome, and she was in my class for a year, this was last year.

Andy: Anybody else had any experience with this?

Woman: I worked with that same girl for two years, I think, yeah, prior to that, and prior to that diagnosis.

Woman: Mhm. It took them a long time to figure out what was going on with her.

Andy: And do any of you currently have any children? I guess you don't have any children with these? If you think about, maybe it's gonna be difficult, because if you haven't had children with these diseases, let me just throw this question out. What concerns would you say you would need to have addressed to make you feel comfortable if you had a child w/ a genetic or metabolic disorder enter your classroom? What are the concerns that you would have, so you would feel comfortable having that child in your classroom? What are the things you would be worried about?

Woman: When I had Sam, I, she, it was also an immune, she had a low immune system, so she was always sick, and one of the things that I was really concerned about is, was I keeping the classroom clean enough for her? I didn't want her to get sick, so I was always trying to keep everything clean.

Woman: And there's safety, I think would be my biggest concern.

Andy: Safety issues, yup.

Woman: To know as much about the disorder as I could.

Woman: Um, I'd want to know about any contraindications for like, movement. Because I do a lot of movement and sensory type of inputs, so.

Andy: So, movement issues, physical.

Woman: And we have the kids, we have them here for 6 hours a day, so they go through eating in our classroom and they go through gym, and contact with other students, contact with the outside during recess, so there's a lot that can come into that area and you can't always control all of it, so you know, what specifically needs to be controlled to keep them, like Angela said, safe.

Woman: And if something happened, we'd need to have protocols or just a game plan for what to do.

Woman: And who on staff should be aware of that student and what they need.

Woman: Any accommodations or modifications that need to be done.

Andy: Educational accommodations? Okay. Um, let me just move on then. If you needed information about a particular metabolic condition or a genetic condition that a child might have, um, where would you find the information that you need? If there were any special accommodations that the child might need or any special things you need to pay attention to, where would you go now to find information about that?

Woman: If they have an IEP, if they're...

Andy: Yeah, so you'd look at the IEP to start.

Woman: Talk to the parents too.

Andy: Parents.

Woman: The school nurse, see if she had any...

Woman: When I'm looking for more information, I do the internet a lot just for other strategies or ideas or things I didn't know.

Woman: I also get a release of records to talk to their doctor.

Woman: I would think that they might come in like with a specialist or someone, not come in, but the family would be working with someone with whom we could speak.

Andy: Any other places you'd go? Um, what would you say is the best way to get information about educating children with genetic or metabolic disorders? You know, for instance, brochures, posters, the mail, internet site, websites, you know, what do you think would be the best way to do it for you? I mean just more like the best vehicle, not necessarily a specific site, but what would be the best way for information to come to you?

Woman: So not where the best information would come from?

Andy: Not where the best, yeah, not where, but the best vehicle for you to get the information? What would be the easiest way or the best way for you to, for somebody to put information in front of you?

Woman: I always start with the IEP, because it really should be specific to that child, so, if there are specific protocols or anything, it should be right in that document.

Woman: If they don't have an IEP, or even if they do, like I had the same student that Missy had, I...internet. Whatever that rare disease is, website is that you can send away for information.

Woman: I find that um, the US Department of Health has good information to, they send a lot of information.

Andy: But how, what format does that come in, is it brochures, or is it online?

Woman: You can get PDF's and yeah.

Woman: There are like chat rooms, not chat rooms, but like blogs or things like that that are from other teachers giving ideas back and forth to each other that sometimes are helpful, what's going on in their classrooms, bouncing ideas back and forth off each other.

Woman: Just having different areas to go to that are easily readable and accessible.

Andy: So just ease of use is an important...um, just think of the kind of information that you'd get, what would be like more important to you, like practical knowledge about the student with the disorders in your classroom, or more specific information about the disease itself?

Woman: I would like both.

Andy: You'd like both?

Woman: Me too.

Woman: Yup.

Woman: I think first the practical knowledge just to know about the student in front of me, but I think I would want to know more about it just in case, you know, something was progressing.

Woman: Right, and by knowing more about the disease, I think you'd understand the student better. The whole student, at home and at school, and just what their life is like.

Andy: Any other things? Um, what I'd like to do now, is to walk through so I can see it for myself as well as you guys see it. What I'd like to do, is just walk through this tool that's been developed by the New England Genetic Collaborative. And what this, this is a mockup, this isn't a real website, but this would be a website, and this is just power point, so please, you've got to squint and pretend that it's, and this is not what it's gonna look like when it's done. This is before we give it to the web designers who can make it pretty and functional and all that sort of stuff. But what I want to get is your reaction to the way it's set up, some of the things that are laid out on it, and some of the information. So what I want to do, is walk through this with you and I'll ask some questions, and if you see something as you go or you want to stop, please feel free to jump right in. But let me walk through it first, so, the front screen, the main screen will look something like this, and we're thinking that initially we'll have a whole drop down menu of specific kinds of disorders and diseases that would be there and you can click on the one that you're interested in. In the future, we'll stop there. So let me just say that first, we'll say that you've got a child with PKU and you're interested in that, finding out about that. It'll take you to a screen something like this with the name of the disorder in the center, and then all the way around it, different functional areas, areas of concern. So if you start, "What is PKU?" at the top, so general information. Emergency plan, some things about fatigability if that's an issue, dietary issues, are there any concerns about increased absences or illnesses or so forth. So you mentioned you had a child with uh, that had an immune system disorder, so that would be some area of concern there. Are there any behavioral supports? Are there any sensory supports or supports for pain that are needed? Things about what happens or if the condition should decline or change, what to look for. If you go on any special trips or functions, information about what to do with that, and then finally, any specialized educational support services. So this is kind of a group of things, and I'd like you just to look at those, but keep in mind as we're going through, if you think of any other boxes that should be on this front screen, that you really think that this is so important I need to see it right up in the front. So let me just kind of go through with this for PKU. So if you click on "What is PKU?", it'll have short information about the disease itself, written in layman's terms, so PKU is phenylketonuria, an inherited metabolic condition diagnosed in the newborn period, treated w/ a special diet, must be adhered closely in order for the child to function well in school, etc. So, it tells some specific things about it and there'll be links at the bottom down here for more information, you can go to, this is the NCBI website, which actually has a tremendous, a lot of information and a pretty good, I'd say the glossary of diseases there is written pretty simply so it's not so hard to follow. So this would be a page with just general information. The other thing that we'll have on each of these pages is a little button at the bottom where it'll pop up as a PDF so you can print it out, so if you want to have it as paper, you'll have it there. And then if you go to the next section, an emergency plan, do you need an emergency plan? Well, for PKU, not really. There is no real need for an emergency plan, so it'll tell you straight forward that no, this isn't an issue for this particular disorder. Any issues about fatigability? Nope, not for this one. Are there any dietary differences? Yes, and it lists the specifics, low protein, low phenylalanine diet, and it goes through all of the different things and about what you need to do or what needs to be done. Supervision needed to prevent sharing of foods, you know, if you've got a first grader who has PKU, I'm sure they'll know their diet, but if some other kid's got something that looks pretty good, they're gonna want to get it and that may not be what they want to do. Not that that ever happens in classroom. So, increased absences, not really, not for PKU. Any behavioral supports that are needed? No, it's essentially not a behavioral issue. Are there any sensory supports, nope. Things to pay attention to for changes in the client's condition, what for new or different learning needs if they indicate a change in phenylalanine levels, watch for changes of puberty or other times of rapid growth or

high energy, because that means their diet needs to be adjusted. Levels are affected by minor illnesses. Involve parents and school nurses when changes are noted, and so forth, so it tells us things to pay attention to here. And then if you go on a trip or special function, if you go on a field trip, that child is gonna need to have their special food diet with them, you can't just count on them being able to eat whatever is at the place. You'll have to have a means of transporting the special formulas that they need for their food, you have to have the volunteers trained in things to pay attention to. Don't let Johnny eat from Sally's lunch over here, so all of those things need to be gone through. And then specialized educational support services, developing a 504 plan, have a setting that includes special arrangements for eating and drinking during the days, because kids will have to have access to their food more often, and make sure that you understand that the executive functioning changes by phenylalanine levels. So, PKU, this is what you see for PKU. It's a condition that more, it's not, it doesn't have a lot of the extra behavioral components or learning components that a lot of disease might have, but it, so it's a pretty straight forward one. Does that make sense how that works? I'm gonna walk you through another one that's a little bit more detailed, so Q22 deletion...22Q deletion, sorry. It tells a little bit about what it is, affected children can have speech problems, learning problems, heart defects, problems w/ calcium regulation, immune function. So this is a more, it has a lot of other facets to it than PKU does.

Woman: Now, are those links like microdeletion?

Andy: Yup, those would be live links so you can see what this one leads to, this links us to [geno.gov](#) glossary that was about that one. So you'll be able to click on that and it'll take you, so this'll all be hotwired on the page so that you'll be able to pick up other information on there.

Woman: That's really cool.

Woman: That is neat.

Andy: I hope you know what micro...if you didn't know what microdeletion was, it would be.

Woman: I can figure it out, but I was just like, wow, I never would have thought to put that out there for someone who might not be familiar.

Andy: And, so, do you need an emergency plan? No, not really for this one. It's not an issue. Yes, there is concerns about fatigability, so make sure you check w/ the parents to understand, there's a cardiac defect that may have an impact on endurance, low muscle tone in infancy. Children have problems, they're clumsy, lack of coordination, and so forth, so it's things for you to pay attention to as a teacher to understand, so you might not, you have a child, imagine, the child moves into your town, it's February, it's in the middle of the year, and you get an IEP w/ the disease like 22Q deletion, and you say, "What is this?". So, this would be a thing to pay attention to. Dietary differences, you know needs, diet issues, any increased absences, yeah, younger children may be susceptible to infections due to immune deficiencies. You could have a number of absences because of surgeries. So this one is a lot more involved, and you might have to be aware of these things and adjust your educational plans. Uh, do you have behavioral supports? Yes, 30-50% meet criteria for ADHD, medications, sensory integration problems are important, 20% of all, 20% will have a psychiatric diagnosis when they are adults. And a lot of these things will start to demonstrate themselves early on, so anxiety disorders very common, so

these are the things you would have to pay attention to in the behavioral area. Sensory supports, sensory integration problems, generally no issues w/ pain. No particular changes, the condition once it's there, it's pretty much there, it doesn't really change too much. Field trips? No real issues here. Nothing that would be different. Um, special educational support services, here we've got a lot of things that you'd really need for this. So, just general things. So consider an IEP as learning problems are common, 66% have nonverbal learning disabilities, IQ's are lower than average, poor executive functioning, poor problem-solving, helpful strategy is to break larger problems into steps. So some concrete things about general issues w/ cognitive ability for this disorder. Speech issues, so um, palatal function is usually impaired, even if the palate is intact, so there's some problems in pronouncing words, hypernasal speech is common, articulation problems common, oral motor problems common, so a number of things to pay attention to.

Woman: Some links would be good on that.

Woman: Some links would be helpful on that one, I'm looking at Julie going, okay, what are those?

Andy: Language issues, language development is slow because of the palatal abnormalities. There are neural issues, receptive language and expressive languages are, receptive language is greater than expressive language. Later in childhood, it reverses, so they can express, but they are not receiving it very well. Language impairment may persist throughout. Fine motor issues, gross motor, they have problems w/ scissors and fine motor issues. Um, memory, rote memory is good, but weaknesses in memory of story details, spatial memory is a weakness, impairment of working memory, so these are things that you would need to know about a child who has this. Uh, reading, stronger than comprehension, so they would read well, it sounds like they know it, but they're not necessarily comprehending what it is that they are reading. They are better at learning to read than reading to learn, because of this, the reading skills tend to decline. It seems like they are reading very well at an early age, but then they don't continue at the same pace later on because they are not really reading the decoded things, but they're not getting it, they're not understanding, they have problems w/ comprehension, they need well structured reading programs w/ emphasis on comprehension, so that the areas that you have to pay attention to w/ reading and then finally in math, it's most pronounced learning deficits due to combination visual spatial learning difficulties, working memory, particular problems in problems that involve abstract reasoning, reading language in the mathematical expressions, so word problems would be a real concern with this child. Telling time is hard. Using money is difficult, um, focusing on number sense first, then repetition and practice, so there's some strategies for how to deal with this. Now, I should say, these are not complete, but we've got people that are specialists in these areas working on each of these particular disorders putting this together. But this is, this is more the kinds of information that you would be getting, and let me...go ahead.

Woman: Will there be links like for additional resources under each category or like for more information?

Andy: We will note that. Do you think that would be a helpful thing to have links on? Okay, when possible. I don't know if it'll be there for every one, but when possible.

Woman: Right, but for the math or for other things, or even just you know, one box on the top, one button that says additional resources, instead of putting under each area.

Andy: Okay. Maybe on the front screen?

Woman: Yes. Like one of those yellow buttons.

Andy: Like additional resources right on the front here.

Woman: Yeah.

Andy: Okay, let me go through just the last one, it's slightly different, so sickle cell anemia, what is sickle cell disease? It affects red blood cells, have red blood cells become hard and pointed instead of round and soft. And this one is different than some of the others, because pain is a real issue in this one, it can become very painful for the child. We have to be concerned about that. Um, so we go through some of the things here for an emergency plan, you have pain crises the main reason older children go to the ER and get admitted to the hospital, dehydration can contribute to pain, call the student's primary care physician right away. So this is one where the pain is, most of these other things it's not a major concern, here, pain is not only, it's a symptom, but it's a severe underlying concern when a child has pain. Fatigability, not too bad, but again, exercise and dehydration causes a real problem, so. Are there any dietary differences? Nope, no dietary issues. Increased absences, maybe pain would be the major reason for increased absences and visits to doctor. Encourage keeping up with work and avoiding pain crises, so make sure that you are working with the child to keep them out of those situations. They're gonna want to run and play and goof around w/ all their friends, but your job then is to say, "Let's not do that," or "Make sure you're drinking more water," keeping up with those sorts of things. Um, are there behavioral supports? No needs for behavioral supports. Sensory supports, yes, pain is a major issue, talking about things to do with pain and there is some repetition of things that you see. Um, have the family meet periodically w/ school nurse to discuss pain management, because that's going to be a continuing issue, keep alert for increased number of painful episodes, that's a sign that their disease is progressing. Keep alert for any sudden neurological changes, stroke is a risk for these children, so things to really pay attention to in the classroom. Uh, trips and functions, same sort of issues. You wouldn't think about it, but you know, the child w/ sickle cell, you make sure you have water w/ you all the time, to make sure that they're not gonna be running around and moving around, which is going to be difficult on a field trip, think of some of the outdoor fieldtrips that you would go on, I mean half the point is get the kids worn out and running around, this is not gonna be the case. Airplane flights, not a particular problem. And then educational support services, don't really need any here. So, this is generally what it's going to look like, and what I want to do is just, I'm gonna ask some questions about it, first off, what's your overall reaction to this? Would you find this useful in your classroom?

Woman: Definitely.

Woman: I think so, yeah.

Woman: Absolutely.

Woman: Easy to use.

Woman: Um, my initial reaction is that it's great, but I don't know if there's a way you can put

some sort of disclaimer on it that every child is an individual and not every kid fits those molds for those specific diagnoses, because I just see people using it like, “Oh, I have a kid w/ PKU, this, this, this and this are gonna happen,” you know? I don’t know, does that make sense? I’d just be weary of that.

Woman: Yeah.

Woman: That it’s just guidelines, that it’s not rote for every child.

Woman: Yeah, right.

Andy: Any other overall comments about this?

Woman: And at the same time, I was hoping that there would be a way to have like a blank template somehow, so that we could use that to put our own children in there and to use those templates to make our emergency plan and to give to our classroom teachers, maybe just like as a special ed teacher, saying, “Here are your sensory supports and you behavioral”, but everything in one big packet, or?

Andy: Maybe like to be able to print the, all of the information about that to give to a teacher.

Woman: Yeah, exactly.

Woman: And what you’re saying, I was thinking the same thing about the emergency plan, if there was like a sample emergency plan, so this is how you might set up a plan for a student like this, so that it could be in a file w/ their 504 or IEP or whatever they might need.

Andy: Okay.

Woman: It seems very easy to use.

Andy: And it would be faster than...

Woman: No, absolutely.

Woman: I’m wondering if um, social needs or skills would have to come in anywhere if that’s ever an issue, but I’m not sure if it would...

Andy: That came up at our last group, and that went right up there for social needs.

Woman: That’s a good point.

Woman: I would think it would be.

Andy: You would think that having a button here for social needs would be good?

Woman: That’s what I would say.

Woman: Yeah.

Andy: Any other general things? What do you? Go ahead.

Woman: The educational supports, you know, you're going to that thing and you're looking for probably more online resources, so telling time is something difficult, have a telling time website, or, there's just so much out there, make it as easy as possible for people to, because you can get lost researching on the internet, so you know, if it's done for you.

Andy: So, this would do the triage for you, it would wade through the good and the bad sites. Okay. I could see the people that put these together saying, "Oh my gosh". That's alright.

Woman: Do you want more specific? I wrote a bunch of things down, do you want more specific things?

Andy: Sure. Yeah. Well, let me ask you this, let me ask the questions and I think hopefully we'll be able to go into specifics. What do you like best about it first? What do you think is the best thing about this?

Woman: I like the organization of it.

Woman: It's like a frequently asked questions kind of.

Woman: I like that it's designed for people in the school system. That it's not just this general thing, it's really tailored to within their school day.

Woman: And it's understandable.

Woman: I was just gonna say, it's not written in you know, medical jargon or anything that we would have to decipher just to help the kids.

Andy: Or even educational jargon.

Woman: The format is really readable.

Woman: And having those links for some of the vocabulary that comes up so if you didn't understand it, it's right there. And even if it's not, like a link to another website w/ just like a definition, a brief explanation, 3 or 4 sentences for whatever that palatable thing was. It had a p in it, but it wasn't palatable.

Woman: You were close.

Woman: Yeah.

Andy: Anybody else? What did you like best about it? What do you like least? Or what do you think are the biggest problems that you see? This might be where specific things come up.

Woman: It's not that I don't like it, don't...

Andy: What are the problems, or what's missing?

Woman: I think that just that more information. It's good information if you know nothing about the disease, but it's also very basic, so maybe to be able to get...

Andy: To have links to deeper, more detailed information.

Woman: I could say, a lot of, like for the PKU, it said something like under condition changes, it said something like, "If learning differences arise, blah, blah, blah," and for sickle cell it said, "If there are neurological changes, blah, blah, blah". Maybe those could be defined.

Andy: Examples. Okay. Some examples of changes to pay attention to. Okay.

Woman: Yup.

Woman: Well, my question for the sickle cell disease, there was an increased absence due to illness, but yet there was no specialized education support, but I wonder if under where there is an increased absence, maybe under the educational support, none needed unless absences are great or something like that? Because they may be academically okay, but if they start missing a ton of school, they're gonna need some support.

Andy: Anybody missing a lot of school, yeah. Anything else?

Woman: And you did say that you have a team of people working on it, right? Just because, like for under the specialized support services and the speech part, and then the language, I just hope that there I somebody knowledgeable in all of those areas working on it, because under speech for one of them, it said palatal differences and under language it said palatal differences, and palatal differences are a physical abnormality, so it wouldn't be under language. And I know you said this is a work in progress, and this is just to show us, but you know, just to make sure it's accurate, and that you have the right people working on it.

Andy: Yeah, they're, each state has a genetics function that's either in health and human services or the department of education, and they're responsible, this is the group that, New England Genetic Collaborative is a collaborative of all of those groups across the 6 New England states and I think the point specifically the palatal thing is that the physical abnormality causes language problems which causes children to come up with other strategies, so they don't necessarily use words and pronounce words the proper way.

Woman: Maybe too, like a button that says something about home and family supports? Because a lot of times parents come in with some more information than what we have, but a lot of times parents look to us for what resources, community resources are available.

Woman: And that's really important.

Andy: Okay.

Woman: I may have missed this part when I was having my coughing fit, but where would we get this? Would this be a program or something that you'd access by going on the internet?

Andy: This would be a website. It's a website. And so you'll be able to get it from any

computer that has a web link, web access.

Woman: So, I don't even know if this is going to sound right or mean. Um, but not knowing, knowing that anything anywhere can be put on the internet, and never sometimes looking things up and they have contradicting information, sort of to go off what Julie said, if I were to open something like this and go into it and see something that I thought, well that is actually not even accurate, it's very user friendly, but almost to the point where it looks like a high school student may have put it together for a project, so that I might not value that it is accurate data. So, I don't know, it sorta contradicts, it's very easy to use, but it almost its simplicity, making sure that it is seen as a valid thing.

Woman: You said this was power point, right?

Andy: This version is a power point for...

Woman: So, maybe it could just be like a visual aspect of it?

Andy: Yeah, we haven't given, the web designers will do a much better job than what you're seeing here.

Woman: Just something that...

Andy: What we want to do is get the structure and layout and the feel of it down first before we give it to the programmers to have them set up.

Woman: So, that's probably what I was thinking. If I just opened something and it was a power point thing like this, I would have no idea who created the power point.

Andy: No, it wouldn't look like that, there would be all of the appropriate connections and links, and all of that information would be on there too. Yeah.

Woman: I'm sorry, I must have missed that part. I'm sorry.

Andy: This is the part where you have to squint and say, "It's not exactly what it will look like."

Woman: I was thinking it would be a power point, so.

Andy: No, this'll be an actual website that'll be monitored and updated, that's why all those live links that you see in there, that'll pop you right to other places, the more information, it's easy to get more information put on there, it's just adding the link to it, we would have a programmer that would be monitoring the site, but actually, what do you think about the idea of having a way to send information or questions back to the people who are running this?

Woman: Oh, that's a good idea.

Woman: A discussion board?

Andy: Either a discussion board, okay?

Woman: So, would it be like a website that you would sign onto and like have a password and stuff? I'm just thinking like if say as a parent, I'm just looking, and I click on this and then I see all this stuff, and you know, there might be some stuff in there that their reading and then they go back to the school and say, "Hey look, I saw this and why aren't you doing this?". I mean, not that, that's not a bad thing, but still.

Andy: Do you think parents should have access to something? Who do you think should have access to this sort of a?

Woman: Everybody.

Woman: I think so too.

Woman: I think everybody.

Andy: Because I should say that one of the things that we are hoping to do with this is if you go back to this front page...

Woman: We have to educate the parents frequently, so, in order to be able to refer them.

Andy: One of the things we're hoping, we're discussing in the future growth of this, would be initially what we're building this for is genetic and metabolic disorders, that's the purpose of the grant, and it's for the classroom teacher, people in the classroom, paraprofessionals, but one of the things we're hoping to do, is be able to include a lot of other disorders, so for instance, ASD would be on there. And other things we're commonly faced with, so, imagine any child w/ an IEP, hopefully we'll be able to put that kind of information on there. Another thing that we're hoping to do is have it, the information specialized for the age of the child, so if these children are you know, early elementary school vs. middle school vs. high school, are there different things that are appropriate or you'd have to pay attention to at different times. And then the third area that we're looking at doing is making it available, having specific kinds of information depending on what your role is. If you're a teacher, these are the kinds of, the classroom person, these are the kinds of things. If you're a parent, there are the things that you need to know and should be aware of as a parent about these sorts of things. If you are a pediatrician, because frankly pediatricians don't know a lot about this stuff. If you are a pediatrician, what are the kinds of things that you would need to be aware of, or that you would need to make your parents aware of or schools aware of, in a child with these sorts of issues. So, our, looking ahead, we're hoping to be able to expand this platform to include a lot more kinds of information.

Woman: And maybe then like questions for parents to ask at an IEP meeting, questions for teachers to ask at an IEP meeting, like sample questions.

Andy: Okay.

Woman: Would you say it's more of an awareness website than it is like, I guess I keep going back and forth in my head about if you click on the 22Q deletion one and then if you go to the educational, special ed whatever, and then math. So, like that tells you this is the area where they have the biggest learning deficits due to x, y, and z. Now the last one, focusing on number sets first, then repetition and practice. That would be more of a recommendation, right?

Andy: Or a strategy.

Woman: A strategy. So maybe there could be a button for, I don't know, the characteristics, learning characteristics and supports, or, I don't know, I keep going back and forth in my head as to whether or not it's more of an awareness thing or are you giving recommendations for education?

Andy: I think it's designed to be both. Awareness of particular issues, but also information about strategies that have been tested. All of the information that's here will be best practices, and that's the things that have been shown up here are best practices for dealing with this. So, it's best practices through genetic organizations and educational organizations.

Woman: So maybe that, what you just said should be like one of the links also. You know, like an overview of our program or like as soon as you...

Andy: Just about what this organization, okay. Yeah, that's good.

Woman: Exactly. So that....

Woman: Like a mission statement?

Woman: Yeah. Wow that'd be good.

Woman: So people understand.

Andy: What this is, why this is here.

Woman: The why behind it, yeah.

Woman: If there would be more recommendations added, you know, maybe not to put on another link, but under like math abilities, just having another heading, recommendations for teaching.

Andy: Mhm.

Woman: Because, do you think there'll be more recommendations like other than the focusing on the number sense.

Andy: Oh, for this?

Woman: Yeah.

Andy: I would, I, I'm a political science professor, asking me about? Yeah, this is not a fully developed for any of these.

Woman: So, I would think for me, I would like to see the recommendations for math under the math supports link.

Woman: So, almost if you would click on the math supports, then you would see at the top that it's due to and it's pronounced in this way, and then here, like subheadings.

Woman: Yes, subheadings.

Andy: Okay.

Woman: Now, do you think that they'd be tying that into the age of the children? Like what they should be learning?

Andy: Again, that, the first pass I think is just to get it as, get it down, probably too much information to have all of the ages all on one thing, and then pull it apart and focus it on different ages and frankly as they learn more about these disorders and issues in dealing with them and treating them, that information will change regularly, so it's gonna have to be continually updated. I think my battery is going to die on me, I think it just did. That's alright, we're almost finished, you saw what it was right?

Woman: To have the last updated statement on, would be good too.

Woman: Oh yeah.

Andy: Okay, yup. Okay. Any other things that, or let me ask you this, how often do you think you would use something like this?

Woman: Whenever we got a kid with one of those things.

Andy: Suppose you had a child with one of those disorders, how often do you think you would use it for that particular child? You know, once that child is in your classroom, you've had them in the classroom for a month or so, do you feel that this would be something that you would refer to, or is it like a one time?

Woman: I think we'd keep using it.

Woman: If those links w/ more information were on there, I'd probably be on there at least weekly.

Woman: I'd be bookmarking, if there were more recommendations, I would be going to that regularly and like questions to ask at meetings.

Woman: And if there was that discussion forum, because they are so rare. A lot of these are so rare, so being able to.

Woman: It would definitely be helpful.

Woman: How are you getting information out to people about this website?

Andy: That was one of my questions, what do you think would be the best way to get information to teachers or paraprofessionals about this?

Woman: Well, who do these kids go through to get diagnosed?

Andy: They'll have to go through some sort of physician. I'm thinking for you, for, for...

Woman: I'm assuming we'd all read the report. So, if that is the last website on the report for more information about educational concerns...

Andy: Oh, okay, I gotcha. Okay.

Woman: If physicians were including it, then we'd know.

Andy: So, through the physicians or the people that are giving the reference.

Woman: People may not realize though how helpful the site is though unless they actually have someone walk through it with them.

Woman: Even maybe a brochure or not to get tossed to the side, but um...

Andy: One of the things that the, the strategies they've been looking at doing is to go to in each state to teachers' conventions or conventions or the meetings that the state people have meetings with principals and school boards and school administrators, to go to all those and give them a little dog and pony show about what it is about, and how it works, and they would bring it back to their schools.

Woman: Special ed.

Andy: Special ed conferences would be another. Are there any other, can you think of any other conferences or that you would have in the state that you think?

Woman: What about that UNH day that we do? Every two years, that SES day.

Woman: That's in March at the University.

Woman: That'd be a good draw.

Woman: But maybe even having if professors at schools know about it to hand out to interns and, I definitely went back to look at stuff that I had from classes, or there's always interns here, so they're bringing it in to show the teachers.

Woman: And if the local specialists that the families are working with, you know, are familiar with it, then...

Andy: Pediatricians in particular would be a group that we would want to go to their annual meetings, conferences, to get this information to them.

Woman: And NEA to each state's NEA.

Woman: Even just email, we sometimes get information of new things to locate on email and they can get forwarded to us from our SAU, so sending the information or the link via email to

different SAU's.

Woman: Special ed directors and then they could forward it on.

Andy: Please pass, please distribute this to your teachers. Yup. Any other ways you think would be good to get this out?

Woman: I think if it does what it's supposed to do, then you know, if I use it for a kid I have, you know, and then I hear that Holly is getting a kid w/ another disorder, I might you know, your hope is that it's a well enough organized website that teachers use it and then tell their friends. Yeah.

Andy: They're gonna want to use it. Okay. Word of mouth.

Woman: Public service announcements too, I mean, you know, in newspapers and stuff.

Andy: Certainly when we get it to the point, we're hoping that it would be available to the general public. It will be available to the general public. We're not gonna, when we put the site up, it's not gonna be blocked, it's not going to be password protected, so people could stumble on it and use it that way, but I think our goal first for this particular grant is to make sure that classroom teachers and paraprofessionals have access to it. Know about it.

Woman: Well, NEA NH, there is a monthly, well NEA the national, has a monthly magazine and NEA NH has a monthly mini newspaper that we could.

Andy: That'd be a good one. Do you get email for web papers from NEA? Do they send information to you that way?

Woman: Yeah.

Andy: Do you guys read those things, or do you do what I do and delete them?

Woman: I read them.

Woman: I usually glance at them to see what's in them, and then...

Andy: Okay, it would have to be like glowing lights.

Woman: It'd have to be in big, bright letters.

Woman: Coupon!

Andy: Coupon, yeah.

Woman: We get stuff from the Institute on Disability.

Andy: Through IOD? And each state has that sort of a function, yeah.

Woman: And each organization, like OT has a big national organization, speech has a big

national organization, so.

Andy: Again, this is designed originally for New England, but the broader, national organizations that are sponsoring this grant have already said, “You guys get it to work, we’ll go nationwide with it.” So, that’s good that we’ll have a lot more resources to back it up than we’ve got now.

Woman: I think a postcard in my mailbox is a really good, yeah, because I will read the front and back of that, whereas the emails, I would glance you know, the subject, I read the NEA stuff when I get to it, but the postcards, you know something that’s just front and back.

Andy: Is there anything else that we haven’t talked about or covered about this, that you’d like to say? That you think that we should bring back to the people that are designing, building, creating, this?

Woman: Did you say there was gonna be a contact us?

Andy: That’s one of the things we’ll be bringing back to them, yup.

Woman: And I don’t know if there are any specialists who would be willing to, you know, contact a specialist or someone?

Andy: Yeah, I don’t know what kind of resources they’re gonna have at the other end to be able to do it, but if there are suggestions or things like that that you would like, I think it’s important to have that feedback.

Woman: When do you think it’ll be up and running?

Andy: Um, within several months. So hopefully, by the beginning of next year, your school year, it should be up and running.

Woman: You just stole my thunder, that was my question.

Andy: It took a long time just to get the information together to populate the ones here, and if you think of all the genetic and metabolic disorders that are out there, if we, we’re going, we’re starting at the top w/ the most common ones, and then working down into the rarer ones, most common of the rarer illnesses. There are some metabolic disorders where literally there are a dozen people across the country that have it. Those might not get taken care of right away.

Woman: Those are probably the ones people want the most information on!

Andy: That’s a good point. So there is a balance between.

Woman: Right. If I had a student and he or she was one of twelve, I would not know where to get any information, but that’s a side.

Woman: There was one typo in there.

Andy: I’m sure there are typos. You must be an English teacher too, right?

Woman: Okay. When you said he or she, I'm like oh yeah, there was one...

Andy: You guys are a rough crowd.

Woman: We're also very impatient, we want it done now.

Andy: Well, that's important to know, we'll pass that on too, because I don't think there's anything out there like this now.

Woman: No. It would be interesting even to look at the kids that you can't figure out. Like I have kids in my classroom that I can't figure out what's going on with them, just to be able to look at these rare disease to see, not to suggest them, but you know just...

Woman: Just for the strategies.

Woman: Yeah for strategies.

Woman: If there are certain things that you were seeing in the classroom to be able to type them in and see what came back at you.

Woman: Ahh, that's a neat idea.

Woman: A search engine.

Andy: Okay.

#### SMALL TALK

Andy: Well, if there's anything else, or you don't have anything else to say, I want to thank you very much for coming, the information you provided is very helpful. This is going to be very helpful in getting this nailed down so they can really get into the actual building of the tool rather than just prototyping it. I think that, I should say that the background of this, when we first got into this project, the original grant was to essentially make a poster that would go in teacher's rooms and we kept thinking how are we going to do this? And then finally someone said, "You know, if we just did this as a website, then it's multilayered, you can get as much information or as little information as you'd like about these things to be able to expand it as you need it, rather than printing up new ones when you have to make changes."

Woman: Right, that's a lot of work.

Andy: Alright. Well, before you leave, I want you to make sure you get some of these other cookies and stuff. If you have kids at home, bring them home, give them to your kids, eat them on your way home. Again, thank you very much for coming.



**TRANSCRIPTION  
BURLINGTON, VT**

## Burlington, VT

Andy: Well, how about if we get started? You said there was one more person coming?

Woman: Becca, yeah, but she can jump right in, she's a quick study.

Andy: Um, my name is Andy Smith, I'm the director of the UNH Survey Center. This is Tracy Fowler who works at the survey center as well. We've been hired by a group of people across New England called the New England Genetic Collaborative, and they are special educators, teachers, public health personnel, professionals that are working within each of the New England states, and they've got a grant to design a way of providing information to classroom teachers about genetic and metabolic disorders. That was their original plan. When we got in to talking about it and seeing what we could do about it, and me coming in as a researcher w/o any knowledge of the topic, saying they had originally planned to have like a poster design with stuff on it. And they wanted to do a telephone survey, and I'm thinking, it's really hard to do a telephone survey when people don't see what it is that you're asking them about, so let's see, why don't we think about doing focus groups to talk to people about how they like this or not. Once we got to that point, somebody else in the committee said, "You know, we could do this as a web page instead of a poster, that way we could put new information and update it and have a lot more stuff available on it than we would have been able to have if it were just a poster". So, the long, the upshot of those conversations was, we decided we were going to do some focus groups with teachers to see what they thought about this model that we're gonna show today, with the intent of taking the input that we get back from teachers about what works, what doesn't work, what looks good, what doesn't look good, and build it into the model before we actually build the webpage for this. And again, this is an information tool that is designed to be available for teachers, classroom teachers in their classrooms. So, have any of you been in a focus group before? A couple of you have? Good. She raises her hand, so that's very good. Speak one at a time, no side conversations, speak clearly so we can hear your voice. We are recording it, but it's just so we have a transcription of what was said so we don't forget. What I'd like to do is just go around and have everybody introduce themselves. Just use your first name and if you could tell me what your position is at the school so we have a sense of who all the kind of people that participated in this.

Dave: I'm Dave, fifth grade teacher.

Mary: I'm Mary, school nurse.

Sara: I'm Sara, I'm a paraeducator for a girl w/ Rhett's syndrome.

Suzy: I'm Suzy, I teach Kindergarten.

Tea: Tea, I teach Kindergarten.

Leelee: I'm Leelee and I'm an intensive special needs consultant here.

Andy: Well, good. We've got a good range of folks. And what I'd like to do, is when we're going through the questions here, I've got several questions, but they're broad questions. If there is something that you want to comment about, please feel free to. If you don't have anything to

say about it, that's fine too, but I would like everybody to be able to comment about everything that they feel is appropriate. No right or wrong answers. We're really trying to get your experience and your insight into this, because you're the folks who are going to be using this, and we want to devise it so it's very useful to everybody. I'm going to leave this on the screen, we'll go through this in a little bit, but I'm gonna have a few questions first to kind of get a sense of the background of folks that we have here before we get into this. So, the first question I have is, I just want to get your experience with children who have genetic or metabolic disorders. And some of the examples, you mentioned Rhett's syndrome, but PKU, 22Q deletion, sickle cell anemia or other disorders about on those types of disorders. Have you had any students with those types of disorders?

Woman: Would Down Syndrome also fall into that?

Andy: Umm, Down Syndrome would be a genetic disorder, absolutely.

Woman: So, it's not just metabolic, it's genetic.

Andy: It's genetic and metabolic, yes.

Woman: I have taught some children with...

Andy: And what were the disorders that they had?

Woman: Well, one was Rhett, I know that I have...

Woman: Does autism fall? I mean autism isn't really genetic, we don't know, but...

Andy: They don't know really, but, no we're not really going to talk about that.

Woman: Well, we've had William's syndrome.

Andy: Prater Williams?

Woman: Williams is a, is a...

Andy: Williams syndrome?

Woman: Prader-Willi would be a metabolic, that would be...

Dave: What about Prader-Willi's? I've had Prader-Willi before.

Andy: Rhett's syndrome, down syndrome, any others?

Woman: Heart disease in its own way is a genetic...I have had children...

Dave: You know, I think sometimes it's hard for us as teachers to say we've had children w/ this syndrome or that syndrome because we get a child and we deal with the education of the child, but we're not really in tune medically in terms of what is the exact syndrome. Yes we know, but you know, but years down the road, we have no idea, we don't remember, we remember we had

this child.

Woman: Right, we remember the child, not the disorder.

Andy: Fair enough, fair enough.

Woman: But, I mean, we've all been here for, a lot of us have been here for a number of years, and myself being in the intensive end of this, uh, Becca, the question is, he is asking this question to comment, and do we have, about our experiences with children w/ genetic or metabolic disorders.

Andy: And, so we've got a sense of what you've had in the past, do you have any children with any metabolic or genetic disorders currently? I know you've mentioned you have Rhett's syndrome.

Woman: Rhett's. We have cerebral palsy, we have...

Andy: Cerebral palsy, yup.

Woman: What is it when you can't eat wheat? What is that called again?

Woman: Celiac disease?

Andy: Celiac disease.

Woman: I don't know that that's a syndrome, it's not a syndrome, but it's a metabolic...

Andy: It's certainly something that we, we could talk about.

Woman: You have to be really careful, I had one, a child with that.

Andy: Celiac disease. You said diabetes?

Woman: We have quite a few w/ diabetes. We have a Munchkin w/ CMT, where I never remember what that actually stands for.

Andy: CMT? CMT, we'll figure out what that is.

Woman: We're being, there we go, clearer.

Woman: Becca, we are being taped, just so you know.

Becca: I figured, it's okay.

Andy: Just use your first name. By the way, Becca, what's your, what position do you hold here?

Becca: I'm a special educator who also runs the integrated preschool down the hallway.

Andy: Um, so I think one of the things we're hearing from this when we talk to teachers, is there's a broad range of disorders that people have and some that you're not quite sure if they are or not, but this sort of a tool we think would be developed more broadly to encompass a lot of other disorders that children might have. Our original grant is to deal with the specific genetic and some of the metabolic disorders, we're designing a platform, that we can hopefully build out into a lot of other areas as well.

Woman: It's very broad.

Woman: I think we've got a refugee population that do, a lot that are coming in, that do have a genetic disorders that are just being diagnosed now.

Andy: Mhm. If you think about being in a classroom, what are the concerns that you have that you feel need to be addressed so that you can feel comfortable educating a child w/ either a genetic or a metabolic disorder? What are the things that you as a teacher, a child comes in, you get an IEP from them and they have a particular disorder, and you, say you haven't heard of it, say it's 22Q. You don't know what this is, what are the things that you're concerned about as a teacher?

Woman: One of the things I'm concerned about is how does it affect learning if it does? Some may affect learning and some may not.

Andy: Does it affect learning at all.

Woman: So how does, learning, attention, and...

Woman: Endurance too.

Woman: In Kindergarten, we serve snacks, so if it's a metabolic thing, I want to, we serve food, so.

Andy: Food, so will it, do they have any food allergies or problems w/ foods. Yup. Other things?

Dave: I guess a quick summary of the, whatever the syndrome is, and what we're going to see. Also what are the ultimate goals for the child, what can you expect in adulthood for a child w/ a particular syndrome. Are you preparing someone who could still be a college professor, or are you preparing someone who can barely function and you're hoping that they'll just be able to function on their own when they're an adult. So what are those educational goals?

Woman: I think also another concern for a teacher is will this child have help aside from us, because it's too much to ask for a teacher to have to deal w/ the medical needs of a child, so.

Woman: And the limits of the child and the fragility.

Andy: Limits and fragility?

Woman: Yeah, right up front, how fragile and the other thing is the parent piece. I want to know, how has...

Andy: What about the parents?

Woman: How has this affected the family life?

Andy: Okay.

Woman: And what kinds of, what's the, very often the parents need extra attention.

Andy: What supports the parents would need. Okay, out of classroom supports.

Woman: Because they're usually scared to bring them to Kindergarten, because they're leaving them all day and...

Dave: And how to access those supports. Um, how to get those supports accessed for the parents w/o the teacher having to be involved in doing that. To be able to go, what agency or whatever can be contacted so that it's taken over.

Andy: Okay, so resources available.

Woman: For me right now, communication is a huge issue. Just how does the child communicate that they understand and how do they communicate what they want, what they need, I mean for me, I've been with this student long enough where I can sort of read somewhat what she's feeling, but I imagine, when I first started, I was just kind of...

Woman: Guesswork.

Woman: Help! Guess we'll check, we'll see.

Woman: And the information, too, some of the websites and we are so lucky these days to have Google, you can just type in anything and Google pumps the information out for you, but to have something sort of prearranged so the link is there...

Andy: Links that would provide you with more information.

Woman: Yeah, the link's there, again, about the prognosis, what are we preparing, what are lifetime goals for these kids. Uh, I love to see the links that show other kids w/ these certain types of disorders a few years down the road so we can you know, set our sights to help them out in the best way.

Woman: I think as a special educator, the piece that I want most is the up to date, most current information without being overwhelmed. Because the Google information overwhelms me.

Andy: And you don't know necessarily if it's really accurate, up to date, or how valid it is.

Woman: Right, I mean I can guess based on, but, and then the piece, especially when we're looking at the young ages, sorry Dave. But when we're looking at the young ages, I would love a list of resources for you know, what kids look like in books or literature or dramatic play items or, and I think that's kind of off the mark of what we're talking about today, but a link of where

to find not only information, but materials so that it can be in our curriculums.

Andy: No, I like you to think as broadly as possible, if you say that would have been nice to have, or nice to know, that's the kind of things that we want to be able to build into this if we can.

Woman: And then another thing I'd want to know, is how to present it simply to the other children. Because you have to say, "This is a child in our class who needs to be included in this way, and these are the things not to worry about". At first when they have a feeding pump, we have to tell the other children, "Sure, whoever wants to take a look, if it's okay w/ Hannah, it's okay to look at that, but we want to know how to explain to the other kids in a way that's appropriate and not a break in confidentiality. It's overwhelming to the kids sometimes.

Dave: And I think when you go to a website, you want something that's quick, down, and dirty. I don't mind if I want to further detail or I need further information to go to couple of links to do that, but sometimes I need information like that, just something quick to look at, a snapshot.

Andy: Okay. Good.

Woman: Also a list of people that you'd call in, specialists for, I mean, I've found that w/ Rhett's syndrome, it's so unknown right now, and I would just love, love if we had a specialist that I could just talk to, and they could say, "This is what's worked for these girls, this is what hasn't worked, it looks like..." you know, because I think we have autism specialists, we have down syndrome specialists, and they are just very easily accessible, but for the more obscure syndromes, it's really...

Andy: Even if you have access to it by phone or by websites or...

Woman: Yeah, just the nearest ones that are very highly recommended ones, that would be so, so helpful.

Woman: Would it be better too, if you had access and not the parent? Because the parent is giving you their version of what the specialist says, so you almost need a different specialist than the parents, not the child's own doctor, you want somebody else's opinion sometimes as to...

Woman: I'm not thinking of the medical specialist, I'm thinking of like, you know, augmentative communication, stuff like that. Things that we can use in school, not something that would involve a parent, but just for us to call and say, "We're having issues we're trying to figure out, we're trying to find a way that this student can communicate w/ other students, what do you think?".

Woman: Right. I had a student, two, brothers actually, that had Aleesh-Nahan disorder, which I think is a, you know Aleesh-Nahan, have you ever heard of that? It's a cerebral palsy w/ self mutilating disorder, and in that case, I really need, and they, these two brothers also w/o a special thing for their kidneys wouldn't have expected a 20 year life expectancy. It was a very, and I, there was Aleesh-Nahan institute in the town that I used to live in in Jersey, in Gladstone so that that was an immediate link, and actually I did travel down there to meet the doctors who had seen the kids and seen what we were dealing with and I mean, that type of onsite or you know, that is a very helpful tool to be in contact with.

Andy: Okay. Uh, if you needed information about a particular medical condition or any special implications that you would have for assisting with a child with that type of condition, where would you get that information today?

Woman: Google.

Woman: I would go to Mary the nurse.

Andy: The school nurse, okay.

Woman: Woodbine House.

Andy: Woodbine House? What is that?

Woman: Woodbine House Publishers. It's a special ed publisher.

Dave: As a classroom teacher, I'd be going to the case manager for that IEP, yeah.

Andy: Case manager, okay.

Woman: I would probably look online. I look a lot online for, when I have a kid that has some sort of concern.

Woman: And I go to the parents and the doctor.

Andy: The parents and the doctor, okay.

Woman: And we have the CDC here in town which is a very, it's a state run, we're very fortunate here to have the medical school and to have a lot of input here in Burlington.

Dave: Okay. But doesn't that say something? That we're all going to different resources, that we don't really have a procedure for that.

Woman: No. We don't have a procedure. It's a search and search can.

Dave: It's kind of get whatever you can.

Woman: I think that sometimes parents aren't the people we should be going to. I think parent's are going to advocate for their kid, which is what they should be doing, and they're listening to doctors with a certain mind, and we need to go, we need to step away, even maybe not even that child's doctor, but some other person that's not advocating for the parent, but someone who is an informed, you know a doctor that's sort of unrelated to this particular family.

Woman: Very objective.

Woman: Yeah.

Woman: Well, and I think that's the piece about the child development clinic, is that you know,

while it's hard to actually call and talk to a doctor, because there's so many steps to get to them.

Woman: To get to the doctor.

Woman: But they're developmental pediatricians, they're not regular pediatricians, so their job is to be able to be familiar with all of these and say, "I'm assessing using the latest research standardized, normalized stuff, and then provide us w/ readable reports.

Woman: But it takes 6-8 months to get in and then another 8 months to get the report.

Woman: By then they've moved to the next grade.

Woman: Exactly.

Andy: Um, so what do you think is the best way for you to get information about educating children right now, for example, brochures, posters, email, website, in person, what's the?

Woman: Website I think.

Woman: I go to the web, there's a Rhett's syndrome.com, there's like an actual, because that's the only sort of genetic disorder I've dealt with, that's where I've gone is the name dot com.

Woman: When I get, we get barraged as educators with econnections, we get the Stern Center blasts us, we get Howard Center, these are all local agencies that have workshops, and I myself shut down when I get all of that information, and I'm like, I have to pick what I attend to, because I don't have enough brain cells.

Woman: I also go to Merck's Manual.

Andy: Mhm. So, um, if you think about, what kind of information is more important, most important to you, practical knowledge about having students w/ these disorders in your classroom, or more specific information about kind of the genetic basis of the disorder, like the scientific information about the disorder itself. As a classroom teacher, what is more important for you?

Dave: Practical knowledge!

Woman: We're more behaviorists, we're not talking...

Andy: I should say, this was kind of a set up question, but the people from the genetic collaborative I think wanted the, they think that you want to get the scientific information.

Woman: I actually like a little...

Woman: I would get the practical first, and then I would just out of curiosity want more information for myself.

Woman: I would too. It would not serve me to just get the practical.

Dave: No, but it's the practical that you need to do something with.

Woman: On a daily basis.

Woman: But I've got to understand it a little more deeply I think to be an effective practically. Maybe it's curiosity.

Woman: Yeah, I think it's curiosity.

Woman: But it is, it's interesting, to think that one little tiny chromosome can reek havoc.

Woman: It can throw off the whole boat.

Andy: Well, what I'd like to do now, is walk you through this prototype, this is not a website, this is in power point, so, please squint your eyes and imagine what it would look like after we got a web designer who actually knows how to put this together, this was not for the purpose, just to think about it that way.

Woman: I'm just impressed you got a circle with the little arrows inside it.

Andy: Oh, you're gonna be more impressed than that.

Woman: Ohhhh.

Woman: I think, right off, I wish it'd say teaching a child with metabolic disorders, and then do the, because otherwise if you don't know what that is...

Woman: Yeah, PKU is, nobody knew what...

Woman: PKU might be the name of the toy.

Dave: It means nothing to them.

Andy: I'd say the model that we're looking right now for the front page, will be, it'll have about the organization and that sort of stuff, and it will have a line where you can click here to look for the particular disorder that you've got, we're thinking about probably having it for children of different ages roughly, of um, you know, young children through elementary school, middle school, high school aged children so, because kids present with different issues and thing and ways you have to deal with them at different times. And then, ideally, what we'd like to have is another click if you are a teacher, if you are a pediatrician, if you are a parent, if you are somebody else who needs certain kinds of information that would be more appropriate for what you're looking at as the home page, but that's what we're thinking about, it's not locked in stone yet.

Woman: And the more you can break that down, the better.

Andy: Yup.

Woman: Because as Kindergarten teachers, when people put elementary, what happens for a

third grader isn't, as more, as finely as they can fine tune it, 4-5 and 6-8's would be good.

Dave: I agree. I think a 1-2 year breakdown would be better. Also I don't know if there'd be a way to, let's say you get a child in, you don't have a diagnosis, that there would be a different avenue to answer some questions, say these would be good things to do with a child who is presenting w/ these symptoms even if you don't have a diagnosis.

Andy: We may do that, but I have to say, there is some problems getting into who's diagnosing what, and just some, I brought that up actually from the previous focus group, and one of the people from the collaborative said, "I don't know if we want to have teachers diagnosing children particularly," but this question has come up.

Dave: Not as diagnosing, but these are some things you can try if these are the things you are seeing, these are some strategies you might try.

Andy: So, more dealing w/ the behavior.

Dave: And put a disclaimer on it.

Andy: Okay, that's always good. So, let me walk through here, and I'm just gonna, we've got this mocked up for 3 different disorders, and they all have different things that work for them. So let me just go through PKU first. So the first screen is gonna look something like this, teaching a child w/ PKU, and then it'll have all these buttons around there to deal with some specific things about, that you might need to do. So, I'll click over here, first, what is PKU? So you click on that and it's designed to give you pretty quick information about, PKU stands for phenylketonuria, it's an inherited metabolic condition that is usually diagnosed in newborn children and it's treated w/ a special diet that must be adhered to closely in order for the child to be functional in school. If not following his or her diet, they usually become physically ill, but may not be, behavioral challenges, but will not be able to think as well as when they follow the regular diet. More information can be found by going to this NCBI, and it's NIH, actually it's a really good glossary of, medical glossary.

Dave: But when you say something like, but may have behavioral changes, I would like to see something, such as. So we have an idea of those sorts of changes.

Andy: A little bit more information. Okay.

Woman: This also just makes it sound as though it's totally a diet thing.

Andy: Well, actually, it says...

Woman: Well, behavior, but it's all based on diet.

Andy: This particular one is. PKU is really, it's a dietary thing, it's the way your body processes the phenylalanines and it means that you can't drink for example, artificial sweeteners and things like that, it'll really put you out. Um, so there are, it's a special diet that you have to adhere to.

Woman: It's horrible.

Andy: So, we have that. Um, is there an emergency plan, and for PKU, not particularly, no particular needs in this area. They may have some individual needs that are unrelated to this specific condition, but for PKU, really not, it's not something that you would think of as needing an emergency plan. Is there any problems w/ fatigability? In this case, not really.

Woman: But that was a little deceiving to me, because it said, easily fatigued, is that what it said? So instead of saying fatigability, it says easy fatigability which led me to think a child w/ PKU has easy fatigability.

Andy: Well, and I think you'll see, all of these buttons will be around all of the different disorders that we have.

Woman: But if it said fatigability, that would not mislead me.

Andy: So if it said fatigability.

Woman: So, take the easy out, yeah. If you leave it that way, then you're gonna find that information whether they are easily or not.

Andy: Or, yup. Are there any dietary difference. Here it says, yes, need a low protein, low phenylalanine diet and things that you would need to do. Allow your child to bring appropriate snacks and food. Allow access to a refrigerator because there is a special formula that's needed. Um, allow access to the microwave or refrigerator, involve the parents to make sure that on special days the student has a treat that's appropriate for them. So you know, you think if you're having a birthday part or something going on, Johnny might not be able to eat that, you've gotta have something else available for him. Talk with the parents to determine what foods are allowed, well make sure that you have the school nurse involved with this. If there are sports and school activities, you'll need to have additional low protein snacks, because they do have easily fatigability here. Make sure that you work w/ the cafeteria staff, so they understand the needs here. And then, supervision is needed to prevent sharing of foods, because think of little kids, they see somebody else who's got a cookie, they're gonna grab it. Most kids with this disorder by the time they get up to school, they've had to deal with it and they understand those limitations, but kids will be kids.

Woman: It seems to me that you should have involve the school nurse at the top, because that's sort of...

Woman: You!

Woman: I just think that's the most important one of all, is that, that should be first, don't do this alone.

Andy: Okay.

Dave: Also, I mean, prior to this one, you clicked on two buttons, do they really need to be buttons, or can the information just be there if you go back to the button page. Where it would say, no fatigability issues, no emergency plan necessary, so you don't have to keep clicking on things that really aren't gonna be...

Andy: Yeah, and I think the reason we have this, if you see some of the other ones, we're trying to design a platform that's the same, so it's the same visual look for all of the different disorders, but that's a good point, we think that it's not necessary to have those buttons. Or one of the things we're thinking about is, if something is not needed for that particular disorder to just have them dimmed, so there's no link to it.

Woman: Or a different color?

Woman: That's a good idea.

Andy: Yeah, dimmed down, yeah, so they don't look like they're....

Dave: I hate going to a page that didn't give me any information.

Woman: When you're looking at this, and assuming I'm making the assumption that off the webpage we'll be able to click on each of these buttons and get individual, that individual page, what I would love to see is on this front page of this disorder, once I get to diabetes, to be able to have a print all materials button.

Andy: This has come up before too, and we are going to have PDF's available for all of these pages, and then we've talked about having an overall PDF document for everything.

Woman: For everything. Because if I can print off you know, if I'm only worried about the increased absences, then I'm only gonna read that and print that, but I would love to be able to say, "Here's resources".

Woman: I get so excited to be able to give feedback, this shouldn't say increased absences, it should say absences. It's just like the judgment of easy fatigability. You're just answering where are we at with absences.

Andy: Yeah, I think these were designed to be questions, they probably have question marks after them, are there any increased absences due to illness? Are there any behavioral supports needed? So this is, but the wording there, I think that's important that we work on the working .

Dave: But, again, are there any increased absences, to be able to just put a no right next to it, so that I don't even have to go to it.

Andy: Okay, I gotcha.

Woman: Saves time.

Andy: Behavioral supports, nothing really needed for this. Are there any sensory supports or supports for pain? No. You would really want this one. Any condition declines or changes? Yes, watch for new or different learning needs that may indicate changes in phenylalanine level. Watch for changes with puberty or other times of rapid growth or high energy expenditures or need for protein increases, and they have to have the diet adjusted. Phenylalanine levels are affected even by minor illnesses. Involve the parent and school nurse when changes are noted, involve metabolic team if questions arise about the conditions and/or changes to the child. So

some things to specifically pay attention to there. And I should say, these are not complete for these, this is more of a, for you to get a sense of what's going on here, so are there any things w/ special trips or functions if you're going to something? Here, yes. The child needs special foods to be taken with them, make sure you involve the parent. Transportation of the special formula will have to taken into account. Volunteers are gonna have to know and understand this, that they can't give them a cookie like the other kids have. Making sure they have supervision around eating situations or whatever. So they go back to that eating aspect. And then the final one, are there any specialized education and support services needed? In this case, consider development of a 504 plan, which I don't really know what that is.

Woman: We do.

Andy: But you guys do. Setting to include special arrangements for lunch and drinking formula during the school day. Make sure that you know that executive functioning and activity level are affected by phenylalanine levels for this. So, but there really isn't that much here, I'm gonna show you some of the other disorders, they have a whole series of extra buttons on here that go into specific special educational tools or techniques that you will need.

Dave: Is it just us Leelee, or would you need a 504 plan for a child like this anyway?

Leelee: It depends on whether the student is, if we are assuring ourselves that the student is getting what he or she needs. And if someone says, oh, no he can eat a cookie, and it's a, it brings in a little more structure to the program.

Woman: You know what's not, if you flip back to that open page there, one of the pieces that I look for when I have child w/ a disability that I'm not familiar with or when I'm looking for pieces to train my paras or you know, because I'm in that special educator role, or to train other educators, it's often nice to have who else might be involved in this process. Like I know from reading that, if the child has PKU, that it's a dietary issue, so there's probably a nutritionist and the school nurse is on board, but you know, who else is their outside team? Because not that we're gonna, not that like involving or not involve me as a special educator, but who should be on the team, so when I'm a case manager for a kid, both I can say, "Oh, we need more information on", and it's kind of that spark plug like, "Oh the family doesn't have a nutritionist, we should help them find that". Because doctors don't know everything either. You know, who else should trigger to be with us.

Woman: Now after seeing all of these, within the circle and that whole time I kept thinking what happens if he eats a cookie? What happens if he eats meat? So, I don't know, like I would like to know, like what if I accidentally gave this kid a cookie? Is he, I mean there's no emergency plan, but is he gonna drop down and have a seizure or is he gonna be like celiac disease and have like a horrendous stomachache that's kind of like, oh well, sorry. I mean, what happens. I'd like to...

Woman: And what should you do.

Woman: Right, and what should I do, so if there's no emergency plan, then what, so what's the big whoop? What is PKU? I've honestly never heard of it, so I wanted to know what happens if an accident happens.

Andy: So, more information about what would, in this particular...especially dietary based disorders or that have a dietary component.

Woman: Yeah, since it's such a huge thing.

Woman: So, that could be a box, what if there's a breakdown in care. What if you make a mistake? Big box.

Woman: Just because there is, there is such an issue about diet, what happens if I mess up the diet?

Woman: Well, Mary will tell us too.

Woman: What if Mary's out?

Dave: I think you raise a good point, what if you're on a field trip or something, usually you have access to a computer, what if you don't have access to other things?

Woman: Well, I have my Iphone.

Andy: Let's go to one that's a little bit different. 22Q deletion. You've got the kid that walks in, they've got an IEP that says 22Q deletion, what is it?

Woman: We actually have children in the Burlington school district with this.

Andy: So, it's a microdeletion of chromosome 22. Affected children can have speech problems, learning problems, heart defects, problems w/ calcium regulation, and immune function. Got some learn more at...

Woman: Do they have facial anomalies? It says cardiofacial, so they must have some kind of facial recognition, like William syndrome looks like.

Woman: This is, if I'm not mistaken, this is part of that charge syndrome, that does it affects like 6 body systems. We have a preschooler with this. Now that we've seen the full name and not just 22Q.

Andy: Is there an emergency plan necessary, not really for this one.

Woman: There should be if there's a cardio?

Woman: If it's cardiac you would think there'd be some...

Andy: Well, I don't know, I'm not... the people that put this together are geneticists that hopefully know more about this.

JOKING AMONGST EVERYONE, LAUGHING

Woman: He's not giving us copies of it, so we can't hold him liable.

Andy: So here on the page about fatigability. Make sure you check with parents to check if any underlying cardiac defect may have an impact on endurance, they typically have low muscle tone in infancy is common and may continue into early childhood. Older children are often clumsy and they have problems w/ coordination. So these are things you need to know about that. Are there any dietary differences? Nope. Any increased absences due to illness? In young children, may be more susceptible to infections due to immune deficiency. Other causes of absences are possible surgeries for cardiac defects, multiple specialist appointments, palatal abnormalities, so yes. These people have some serious physical things that are gonna have to be addressed. Are there any behavioral supports that are necessary? In this case, 30-50% meet the criteria for ADHD, sensory integration programs are important to help w/ self regulation problems. And it says that 20% will have a psychiatric diagnosis as an adult, anxiety disorders are very common with these children. So there's information that you need to know about specific behavioral supports.

Dave: So they meet the criteria for ADHD, so are there going to be treating ADHD then, or is it just that they're showing ADHD type symptoms? And that this is totally separate, I mean? That just, ADHD is so, unfortunately so common nowadays that...

Woman: That becomes your other health impaired. You sort of clump it into another category.

Andy: I think what they're saying is that if you see the child that exhibits these kinds of symptoms, it's not an uncommon thing to see children with this particular disorder to have that.

Dave: But they won't necessarily have to take medication for ADHD.

Andy: It says medication such as, Methylphenidate.

Dave: I've never heard of that for ADHD.

Woman: It's the new Ritalin.

Andy: Are there any sensory supports that are needed? Sensory integration problems help w/ self regulation. Generally no issues w/ pain in this case. It's not a real problem. Are there any condition declines? No, not typically, it's usually, it doesn't necessarily get worse, it's a serious disease, you treat the medical problems early on, but it doesn't really get worse. It should be fine. Are there any issues w/ special trips or functions? Nope, not really. And then for specialized education support services, here you see where we've got a lot more information available. So there's some general things available, yes. General cognitive ability, consider an IEP as learning problems are common, 66% have nonverbal learning disabilities, typically they have low IQ's, typically have poor executive functioning, the ability to approach new problems and solving problems is a difficulty. Helpful strategies to integrate, is to break larger problems into steps to provide prompts and then synthesize parts into whole. So, this is again, not complete, but the kinds of information.

Woman: Right, and it seems very basic actually. When you know, as a special educator, I mean those would be just the kick off kind of things.

Dave: But if the IQ score isn't so low, would they even qualify for an IEP, or would it be something else, I thought you'd have to have a discrepancy of a certain amount.

Woman: Well, it says IEP, but I mean that's the first step, it says is learning problems are common.

Dave: But don't they have to have a discrepancy between their IQ and their performance level in order to qualify them? Or would they end up w/ a 504 or something.

Woman: Too standard deviations below the norm.

Andy: And I think that's what you would be getting, if you get to 75 or 80, that's, the average IQ is 75-80.

Dave: Pretty low. Between what they're actually scoring and what they're performing, isn't that how you determine the IEP? It's not where they should be at, it's where they test at.

Woman: That's a good question, but there is the LI Coding which is different, where the learning impairment comes in. Good question and I don't know the answer.

Dave: I'm sorry, I'll try to shut up and listen.

Andy: Here's a question about speech. Speech issues and it says, yes, the palatal function is impaired even when the palate is intact. hypernasal speech is common. I'm looking at these, it probably would be helpful to have English up there rather than the terminology. Global stuff, articulation problems are common, oral motor problems are common, so there's a number of speech related issues that you need to be concerned about as a teacher.

Dave: So, as you say, those are, that's language that we're not going to understand, maybe having it underlined, where you'd click on that and get the definition or an English definition.

Andy: In fact, that's one of the things we've got talked about is having the terms, anything that's an important term that you'd want to have information highlighted and linked to the glossary, NIH has this glossary of information. That's a really nice thing. Then are there any language issues. language development is typically slow, somewhat due to abnormalities, they have neural difficulties. In early childhood, receptive language is greater than expressive language, but in later childhood, expressive language is typically better than receptive language and there is some language impairment that may persist throughout with these children.

Woman: Is that in a larger font because that's the most important? That last line was in a larger font, are you trying to use fonts to make an impression?

Andy: I don't think so, it may be though. I'm, no, it's just the bullet point.

Woman: I see, okay.

Andy: Any fine motor issues? Yes, hypotonia has an impact on both fine and gross motor. In school my present w/ difficulties in writing and using scissors, etc. Fine motor skills may be impacted by both the hypotonia as well as spatial difficulties.

Woman: You don't need to say at school, you can use scissors and write at home.

Andy: Yup. Okay. Any memory issues? It says rote memory is a strength. Weakness in memory is story details, spatial memory is also a weakness. There is an impairment in working memory, the ability not only to store information, but to manipulate it. So there are some definite memory issues w/ children w/ this particular disorder. Are there any reading issues? It says, reading, decoding, and phonological abilities are stronger than comprehension, they are better at learning to read than reading to learn. Because of this, reading skills tend to decline over time, not so much because they are actually declining, not so much because they are actually declining, but the perception is that they're not keeping up with the comprehension. There are problems w/ comprehension, the ability to read or hear or see various pieces of information and put them together into something meaningful, and they need well structured reading programs w/ an emphasis on building comprehension.

Woman: I like that one, that's a good slide. Very specific.

Woman: It make me wonder, with support, are they, can they attain, I'd be curious to know, with supports we have seen children obtain a reading level of... so I don't know, I'm just curious, can you get to a reading level of 12<sup>th</sup> grade or what's the average reading level?

Andy: Okay, and then the last is math. This says this is the area of most pronounced learning deficits, and it's basically based on the combination of visual spatial learning difficulties, working memory impairments, and weaknesses in problem solving, particularly pronounced in abstract reasoning, converting languages into mathematical expressions, telling time, using money, and focusing on the number sense first, but then repetition and practice afterwards seems to be the way to go with this.

Woman: That's a helpful tip.

Woman: Yeah.

Andy: And I do like this one, because I think the one's that you are saying are more helpful are the ones that tell you, these are some things, strategies for you to use.

Woman: Specific.

Andy: So more of the strategies if there are some available would be helpful. And even if there aren't any strategies, maybe that there's an indication that this is something that you've got to deal with. So let me go back to um, that's what we have for 22Q and then the last one that we've got here is sickle cell anemia.

Woman: On your opening page, I'm just gonna keep adding buttons here, but you know, I know that a couple of those slides gave us, you know what you managed to click on the what is, we had the definition and then it sent us to the NIH website, but I'm wondering and one of the pieces that you said at the beginning that you thought would be helpful was not this overwhelming I type it into Google and I get the world, but would it be possible or would you guys be interested in doing a button that was like website specific to this. Like, I would find that useful.

Andy: Online resources.

Woman: Online resources, or resources in general. But I would find that more useful as I clicked into sickle cell, I'm already interested in sickle cell, and now I'm going here, rather than going to the NIH website and then going into their list of things to do after I've gotten, you know, NIH to sickle cell, to websites to resources. Or I'm already here, it says sickle cell, I can click here, here's a list of websites.

Andy: So, on this front page, you'd like to see a button here that said, for more information, more resources about this.

Woman: More resources, websites, books, blah, blah, blah.

Andy: Okay, that's good. Let's go through sickle cell. And I'll just let you guys read it, I don't need to read it for you.

Woman: Now this is particular to African Americans and...

Woman: Does it say that anywhere here?

Andy: I think it does. If it doesn't, it should. It's not unique to African Americans.

Woman: It's not?

Woman: And is that really super important?

Andy: It's more common in African Americans, much more common. It's like breast CA is more common in European Jewish women, but it's also common in other people in men.

Woman: I've actually heard that.

Andy: And actually men die from it more often than women. So, that's some information about sickle cell anemia. Is there an emergency plan needed for this one? Yes. This is a very painful disorder. You may have to, pain crisis is the main reason they have to go to the ER or admitted to the hospital. Dehydration can contribute towards pain. Call the students primary care physician. This is serious pain that develops with this. Fatigability. It says extreme or prolonged exercised can bring on a pain crisis because of dehydration.

Woman: Dehydration, right.

Andy: Make sure that they get a lot of fluids. Any dietary differences? No. Any increased absences? Pain crises are the main reasons for absences. Pain medications make it difficult for you to continue school work while you're out. So pain is the major issues here. Any behavioral supports? No, not really. Sensory supports? Yeah, supports for pain.

Woman: I like the emphasis on hydration.

Andy: As a strategy, it's a useful thing to know.

Woman: Just emphasize it over and over, things like that, I find very helpful. Because if I read

that over and over, I feel like I'd be sure if I had a student like that, I'd be like, "Keep drinking water!"

Woman: And the PE teacher would need to know that more, and the other one w/ the speech stuff, the speech therapist would be.

Woman: Well, that's where the case manager would be part of that.

Andy: Are there any condition changes? And, with special trips, gotta have a water bottle, prolonged exertion, high altitude is a problem if they're on an airplane.

Woman: And we just fly to Florida all the time on those field trips. I rack up those frequent flyer miles.

Dave: But it is good to get, because I mean some of these kids get involved with like Odyssey of the mind and stuff like that.

Woman: Exactly.

Andy: And in this case, there aren't any real special educational issues. This is not an educational or a behavioral issue, this is a physical problem that's there. So what we tried to do here is bring in a number of different disorders to kind of show you the range of things and what would be helpful and not...but I think what I'm hearing here is that if something isn't a real issue, maybe have that dimmed down or not in this area would be a helpful thing.

Woman: So when I went to the initial web, your initial, it would be, it would have a list of syndromes, right? It would be, and I'd click on whatever I wanted more information about.

Andy: Yes, and the idea is that there are people working on these background things, you can see it's a lot of work to put these together and it took people just to put these three together just in the form that they are now, which is not complete, it took a long time, but I think one of the values of having a web based tool, is we can continue to add to it and monitor it. So my sense is when this gets rolled out first, it'll have probably a dozen or so of the more common, not necessarily the more common, but some of the ones that you really would need to know about because they present some special challenges for teachers. I imagine that there are some very unusual ones that parents or doctors are going to be much more involved w/ the school on these.

Dave: Now, will you something on the website where people can provide feedback or ask questions so that you can continue to update?

Andy: That's come up in other places. Yup, a feedback loop is something that we will have built into it, yup.

Woman: Um, well also, well, I hate to keeping taking it back to Rhett's syndrome, but that's what I'm dealing with, so um, I would find it very helpful if there was a link to games, the girl that I work with, she has no use of her hands, she's not verbal, but she's very drawn to the computer, and I'm constantly looking for things for her to do online. With games or reading, reading programs that are accessible to anybody online. If there was sort of a link for the kids, I

would be so happy, if I had something to do with the kid. That might be, and I realize something like sickle cell doesn't require...

Andy: Right, but it might be appropriate for the disorders where it's appropriate, we could have some information about that.

Woman: How will I find this? You know, when I go into the website, how will I find this, are you gonna send it to the school nurses? That way, this is a?

Andy: I'll ask that question in a little bit.

Woman: Can I jump in for a second, you know, I like, I don't remember whether Suzy or Tea had it, I would like the option to both type in the name rather than scrolling down and have it scroll down, because there's some things I could spell and there's some things where I'd be like I don't know whether it's an f or a p, or oh I forgot the h and it sent me back and error message. So I'd like both options.

Andy: And as you noticed, I think like 22Q there are other names for it as well, and you might know it by a different name. So that'd be good to have like a searchable index. So, let me just walk through some of these things. What's your overall reaction to this, would you find it useful in the classroom?

Woman: Yes.

Woman: Yes!

Andy: Okay, what do you like best about it?

Woman: The information. Information about things that, sort of a kick off to what it is.

Woman: For teachers, because if you went to a parents one, I wouldn't find out about field trips, and I wouldn't find, for me that it's geared toward teachers.

Andy: Geared toward teachers. Okay.

Woman: I love, love the math and reading, where they typically fall, how they, you know, they have issues w/ comprehension, this is what you may need to, not in every student.

Andy: So, the practical strategies.

Woman: Yeah, that I just thought was awesome.

Andy: Okay.

Dave: It's quick, it's not buried in something else.

Andy: And that's what we try to do with this circle, so that people know that there's a lot of things that you have to pay attention to with any child, and in these cases, these are the things you really have to pay attention to.

Woman: But if I'm a classroom teacher, I'm gonna aim more towards that Emergency plan and what it is, and behavioral supports, whereas if I've got my special ed hat on, I'm going for the, like I like that role definition. And I think if it's divided by ages, that would really be helpful to be able to say either early childhood, or elementary, or middle school, or however, it's broken down, so that I'm not wading through the 5<sup>th</sup> or 6<sup>th</sup> or 12<sup>th</sup> grade stuff.

Dave: And again, I said earlier, I wouldn't go more than two grades. There is a substantial difference between a third grader and a fifth grader.

Andy: What do you like least about it? You mentioned a couple of things here, I think those are helpful changes.

Woman: I think the visuals are very simplistic at this point.

Andy: Well, this is, yeah.

Woman: Well, this is gonna be prettied up.

Andy: The colors won't be used. Trust me, there are people who know how to make these things look good and work faster and quicker and link better. Any other problems? You mentioned if there was nothing in the area, make it clear that you don't have to click or make it unable to click here, say there are no problems in this area.

Woman: And I think making them questions vs. statements or making them, fatigability vs....

Woman: That really bothers me. No, it does. It should either be a question or it should be fatigability, not easy, it's misleading.

Andy: Yup, okay. Other things that we could do to improve this?

Woman: I think we've mentioned them.

Woman: I don't know it's going to be prettied up, but videos of people with, video links or pictures.

Andy: Video links if possible.

Woman: I know that's all yet to come.

Dave: But separate from the information that's there, in case you don't want to spend the time, if you need something quick.

Andy: So then perhaps pictures and videos and so forth would be helpful if we could like find those and link them in.

Woman: A glossary.

Woman: It's hugely helpful I think to be able to see.

Andy: The glossaries will be all hyperlinked in there. And we'll have the basic link to the NIH glossary.

Woman: And the updatability I think that's what I've been hearing here is that we want the latest and greatest.

Andy: And I should say, one of the things that came out at an earlier group was, how do teachers or parents know who they can trust with this, the, we'll have some information about the New England Genetics Collaborative, who is providing the information, how it's appropriate information will be there. Um, who do you think should have access to this tool?

Woman: The world.

Woman: Everybody should.

Woman: The teacher in training, teachers present.

Woman: Para support.

Dave: What information is there that you would only want for a certain group? You know, it really isn't.

Woman: It seems like it's targeted toward educators.

Andy: The grant is targeted specifically for classroom teachers, but I think what we've seen as we've been going on with this is that there are a lot of other people who would find this very useful.

Woman: After school programs, our school nurses would find it very helpful.

Dave: Nurses, coaches.

Woman: So, everyone.

Andy: If you had a website like this, if it were available, how often do you think you would use it?

Woman: Until I know what I need.

Woman: Every few years when I get that child.

Woman: Right, like if I had a kid, a year where I didn't have a child w/ a syndrome, I probably wouldn't use it. But then there are other years where you might have one or two kids or my colleague might have one, then I'd use it a lot.

Andy: How about as a special educator or nurse?

Woman: I think when we get a new child, because we get all that initial training and then we

play catch up.

Woman: But as you know, the information changes from year to year and that, I mean I've been here 20 years and I still get syndromes that I haven't. Rhett's syndrome, you know, I've never dealt with that. I had a William's syndrome child. I had never dealt with that before. So, they keep coming up.

Dave: Can you imagine someone coming into your position to sub for the day? You could just send them to the website and just boom.

Woman: Sometimes the child changes too throughout the year, you will see different things happening and you could pop on the website.

Woman: But I think that's the key piece is, you know we get, we get information when we're initially trained. As general ed teachers you kind of get the overview, and then as special educators we get that initial training and then it's been 6 years since I've been sitting there listening to the UVM specialist sitting through the health course and now it's like everything has changed since then, where's the most recent information.

Andy: Now, I'm being cognizant of the time here. What's the best way to get information about this out to teachers or people in their positions?

Woman: Email.

Woman: I think a workshop or a...

Andy: A workshop? Okay.

Woman: I mean we do district teacher professional development or whatever it's called.

Woman: I might not go to that workshop and then two weeks into the school year, in comes the child with, I think I need it when I need it.

Andy: But how would we let people know about it? That this was here.

Woman: Because my school nurse knows that this is available.

Andy: So school nurses.

Woman: And whenever she gets a child with any of the disorders that you list, she gets the updated list and what they're in, then when we get that child with Prader-Willi syndrome or whatever, I'm going to give you a link, or...

Dave: Also the special educator.

Woman: Yeah and the special educator.

Woman: Well, but I think the other piece is there is a Vermont Principal's list. There is a Vermont Early Childhood leader's list which would hit all of the childcare providers who would

also benefit from this, the younger ages as well as the early childhood, and I don't know how much you want to blast it, but nec tec news is an awesome....

Andy: I'm not familiar with that.

Woman: It's an awesome website, it's the something educational technical assistance program. It's like one of those collaboratives. And they send out, do you know about this? Every Friday I get an email that says, this is the webcrawl biggest, latest information and it gives me the link and a sentence and then I can go on and scroll down.

Woman: Like what's on it?

Woman: The new, any time Obama is coming up w/ a, early ed is the list I'm on, any time Obama comes out w/ a change or the legislature comes out w/ a change it'll flag it, and it comes every Friday, so that'll be in it, you know, this is new legislation that is being proposed. If there is a new research study that somebody is doing on a disability or an educational issue, that comes out in it.

Dave: But as a classroom teacher, I'm probably going to be looking for something about this, late August, real early September, I would, I'm more likely to throw stuff out at the beginning of the year, a quick postcard, a quick email, because if I have a child like that, I'm probably going to focus, but it's gotta be, this is for this kind of thing. A child with the syndrome, you can go to this website.

Andy: Okay.

Woman: Vermont School of Nurses Association.

Andy: Okay.

Woman: Facebook.

Woman: That's where I get all my information.

Woman: So a poster in the teacher's room might. If I kept seeing this, you know, if you have a child with any of these, here's a resource for you. Just a simple.

Andy: Probably with a picture of this, because that's kind of the way they, this actually comes from some people at the Institute on Disability at UNH who they like to look at a child w/ a disorder, but there is all of these other things around them that you have to pay attention to.

Woman: I think that if you're gonna use Leelee's idea of training or having a workshop, it should be w/ the school nurses, because then they can disseminate the information, because she's, Mary's the one who says, you have a child coming with diabetes, this is what we're going to have to think about. She also could say, here's the website for you to go and check it out, so you could get some of your questions answered.

Dave: But wouldn't special educators also be a good audience for that? Both.

Woman: Both.

Andy: And hopefully we want to have this set up so you don't need a workshop on it, you just click and go. It's designed to be automatic, you don't need an explanation.

Woman: And I like your print all, because I have a feeling that once I read it now, I want to print it all and put it in my desk and go to it, so I don't have to go on my computer. Take it home.

Andy: We're moving to the paperless office, right?

Woman: But, there's also that, what I'm looking for as a case manager and a supervisor is different than what I'm looking for as a classroom teacher is different than what I'm looking for when I give it to classroom teachers I work with. I want to be able to say to you, here's what you need to know, but this might be the piece that, I want to be able to hand to you, okay, go to this website, here's a snippet of information that'll get you there.

Andy: Any other questions or comments about it? Things you like or don't like.

Woman: I think it's very cool.

Andy: The time frame for this is we should have a prototype web up this summer so.

Woman: Would it also be out there on the web, so that somebody could find it through key words or whatever.

Dave: Can you imagine if you were a sub for a day, to get information?

Woman: That'd be awesome.

#### SMALL TALK

Woman: And does it have to be just metabolic or can it be other things to.

Andy: Now you're getting the point. When we thought about this, the more we thought about it, we wanted to build a platform that is scalable to all sorts of different disorders. So you mentioned autism earlier, something that there's a whole series of things, it may or may not be genetically based for whatever the child is, but there are a whole host of things that would be important for a teacher to have. Current things.

Dave: But don't make it so monstrous that it becomes...

Andy: We want it to be a platform. It may not be 100% for each diagnosis out there.

Woman: But if it's useful, we'll keep going back to it.

Andy: I think that's the key, if we can demonstrate that teachers are using this, then we'd be able to go back and show that people are using it. So, I'm going to thank you very much for your time, it's been very helpful.

