The Design of an IEP Decision Aid:

A Tool for Diverse Parents of Children with Autism

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Abstract

Decision-making is a universal process that occurs constantly in life. Parent participation in educational decision-making is recognized as important by special education law, by special education and school psychology literature (Christenson & Sheridan, 2001; IDEIA, 2004;). Partnership in decision-making is especially important for parents of diverse culture and SES, who participate at lower rates, and for whom participation and partnership may mean different things (Epstein, 2001; Gaitan, 2004). Within that population, partnering with parents of children with autism is a priority due to the complex effects of autism on children's communication, socialization, and behavior, a plethora of available resources and interventions, and negotiation of those resources and roles of schools with the expectations of parents. Decisions that diverse parents must make are often complex and their priorities may be different than those of the professionals with whom they work (Dunlap & Fox, 1999; Mandell & Novak, 2005). One method that has been used in the field of medicine, and to a lesser degree in education, is the use of decision-making aids to enhance joint decision-making between patients and providers or between parents and educational professionals (Giangreco, Cloninger & Iverson, 1998; O'Connor et al 2009). However, when these tools are reviewed, few posit a theoretical basis, and when educational decision tools are evaluated using an international quality criteria checklist, they fall short in addressing specific populations and encouraging parents to identify their values and in a process for making decisions, and focus on professionals as the administrator of the tool.

This study utilized design research methodology to develop a grounded theory

model of IEP decision-making for diverse parents of elementary-aged children with autism in Kansas City, KS public schools and to create a decision aid based in the grounded theory and other sources. Participants report a variety of types of decisions that parents make when working with their IEP team, as well as the interaction and influence of varying layers of child, parent, family, systemic, and relational factors into parents' decision-making process. Participants report four general types of parent response when presented with IEP decisions. In partnership with an Advisory Board comprising parent and professional participants, the grounded theory, decision aid standards, and other resources served as a basis for the design of an IEP decision aid tool.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

Chapter 1

Introduction

Background of the Problem

The process of decision-making is studied across the engineering, business, medical, and education fields. There are certain universals present to this process, including examining all the relevant information about a decision, identifying and evaluating alternatives and the attributes of each alternative and its outcome, and then taking some course of decision action (Janis & Mann, 1977). Helping people make better decisions can lead to better outcomes by improving people's knowledge of their decision options and increasing their capacity as a joint decision-maker. The area of focus in this study is decision-making as a part of the Individualized Education Program (IEP) development process for children with autism.

Parent participation is recognized as pivotal to the achievement of the Individuals with Disabilities Education Improvement Act's (IDEIA) national outcomes of economic self-sufficiency, equal opportunity, full participation, and independent living (20 U.S.C. 1400). A more full form of participation is known as *partnership.* Partnership is defined as "a relationship in which families…and professionals agree to defer to each other's judgments and expertise, as appropriate for the purpose of securing benefits for students, other family members, and professionals" (Turnbull, Turnbull, Erwin & Soodak, 2006, p.110). While participation and partnership are recognized in the school psychology and special education literatures (Sheridan, Warnes, Cowan, Schemm & Clark, 2004; Turnbull, Stowe & Huerta, 2007), in many cases parents are not engaged to the full extent that they

would prefer (Epstein, 2001; Rock, 2000). This is particularly true for parents of diverse socioeconomic and cultural backgrounds, who report seeking to be involved but also being unsure how to pursue such involvement (Epstein, 2001; Harry, 1992). Parents of diverse SES and cultural background are often involved in alternative ways that differ from the expectations of the culture-dominant institutions with which they interact (Lee & Bowen, 2006).

These issues are exacerbated for diverse parents of children with autism. Autism spectrum disorder affects 1 in 110 children (Rice, 2009). Diverse parents experience cultural differences in interpretation of a diagnosis, treatment options, and professional-parent relationships (Mandell & Novak, 2005). Parents making decisions related to the care and services for their child with autism often face complex concerns (Dunlap & Fox, 1999; Tissot, 1999). Individualized education programs (IEPs) of children with autism are the most frequently litigated of any special education category (Etscheidt, 2003). These facts speak to the need for a tool to facilitate decision-making and partnership between diverse parents and schools.

Interventions and models exist that seek to increase understanding of decision-making and to improve partnerships with parents via professional practices or parent engagement (Giangreco et al., 1998; Sheridan et al., 2004). However, these models do not necessarily focus on the aspects of decision-making or have not targeted a specific group of parents for whom the need is great. In the medical community, tools known as "decision aids" are frequently used to support patients in making health-care choices about particular kinds of care (Elwyn et al., 2006). These aids are often targeted to the needs of a

specific group, such as patients with low literacy or patients considering cancer screening. A type of decision aid, designed for use in an educational context and based in grounded theory, developed from authentic parent and professional perspectives could help diverse parents of children with autism to engage in participatory decision-making and to partner with their school team.

Design research is proposed as a methodology for studying decision aid development (Kelly, Lesh & Baek, 2008). Design research takes an iterative approach akin to that of engineering, in which an innovation is taken through several phases to improve its impact, relevance, and social validity. Design research fits well as a preliminary step in the "What Works Model" of education research, which currently sets the standard for evaluating effectiveness of interventions through the use of randomized control trials, minimizing attrition rates, and high quality study design. Using the design research approach allows for an understanding of the factors involved, and thus provides reasoning for exclusion of confounding factors. Partnering with stakeholders in design research facilitates identification of appropriate outcome measures, and buy-in gained through this stakeholder partnership promotes intervention implementation with fidelity (*What Works Clearinghouse*, 2008).

Statement of the Problem

Decisions are made daily, but some are more complex than others. While scholarly work has identified common aspects of good decision processes, each situation that we encounter comes with unique challenges. The IEP team meeting is a decision-making process that needs further investigation. Participants in the IEP meeting include general

education and special education teachers, a school administrator or other representative of

the local education agency, other related service providers (speech-language pathologists,

occupational therapists, social workers, school psychologists) who work with a student, the

student and of course, parents. Parents are recognized by the literature and by the law as

important members of their child's IEP team. However, it is often difficult for parents of

diverse cultures and socioeconomic status to engage and partner with the school team. This

difficulty is aggravated for diverse parents of children with autism who encounter complex

challenges. These challenges include deciding upon appropriate goals and services, while

balancing the desires and needs of other family members as well as available resources.

There is a need for a tool to support parents as they interact with their child's IEP team to

make decisions about their child's education. The tool should guide parents through the

steps of making a decision, weighing the goals and needs of people that are important to

them, taking into account available resources, and understanding what they know and what

they need to know to make a decision. This support should increase parental interaction

with and input to their child's IEP team, establishing a relationship between parents and

schools, and hopefully, will foster parent-school partnerships.

Significance

The theory developed from this study facilitates an understanding of the

phenomenon of decision-making for diverse parents of children with autism in a specific

community. Understanding the components of a decision that are important to parents will

advance the breadth of knowledge available to researchers who study parent-school

partnerships and decision-making processes. This understanding can also influence policy

decisions regarding meeting processes, parent involvement practices, and professional development in relationship-building skills, parent education and advocacy.

While advancing the knowledge base is vital to progress in creating better educational experiences for children, it is also true that if people don't relate to something, they won't use it. This study uses the grounded theory that emerges from authentic experiences and perspectives of a representative sample of diverse parents, ("street smarts") with the theory and knowledge accumulated from years of research ("book smarts") to create a high quality, socially valid tool that is both useful to parents and rigorous in its development. When parents have ownership in the tool that is created, they will use it (Rapoff, 2010). When it is used, its effects can be tested on a larger scale. As the tool is used, researchers and users can begin to adapt its use to fit the needs of different populations so that it can be applied further. As the tool is used on a wider scale, its effects on student outcomes and the relationship between schools and parents can be studied and further understood, with implications for policy and practice. A high quality tool with social validity could facilitate the ultimate goal of developing parent-school partnerships.

Research Questions

This study utilizes design research to develop a decision aid for use by parents from diverse SES and ethnic backgrounds who are also parents of elementary-aged children with autism. Qualitative methods will be used to answer the following research questions, as they pertain to diverse parents of elementary-aged children with autism:

1. What factors (e.g. environmental, behavioral, relational) influence the decisions made by diverse parents of elementary-aged children with autism?

2. What are the decision-making needs of diverse parents of elementary-aged children with autism?

3. What are the necessary components of a decision aid for diverse parents of elementary-aged children with autism?

Through the design research approach, qualitative (i.e., interviews, observations, focus group) data is collected to establish grounded theory that underlies the development and refinement of a decision aid tool.

Chapter 2

Literature Review

Decision-Making: A Universal Process

Decisions permeate human lives. From whom to marry, to selecting a primary care doctor, to career choices, to whether or not to travel to Europe, a choice is made. A "decision" is defined by Merriam and Webster (2010) as "a) the act or process of deciding; b) a determination arrived at after consideration." Researchers across the fields of engineering, behavioral sciences, medicine, business, and education have studied the phenomenon and process of decision-making (Thaler & Sunstein, 2009). Normative models attempt to define how a decision maker *should* make a decision, while descriptive models attempt to describe how people *actually* make decisions. There are some models that attempt to do both. These models are known as *prescriptive* models (Bell, Raiffa & Tversky, 1988). Clearly, there is a desire to better understand the decision process and a drive to improve upon it in order to lead to better decisions and outcomes for all (Thaler & Sunstein, 2009).

Across models, certain aspects of decision-making remain constant. First, there is recognizing and framing the decision to be made. We must know what it is we are trying to decide about before we can go on with the next steps (Prochaska & Velicer, 1997). Decision-makers should know about the choices they have in regard to their decision (Kahneman & Tversky, 1979; Matheson & Howard, 1968). To varying degrees and in a variety of ways, we examine characteristics of the choices, what seems likely to happen, what we desire to happen, and other potential side effects of the choice options (Bandura,

1989; Kahneman & Tversky, 1979; Rosenstock, 1974; Yoon & Hwang, 1995). According to social learning theory, decisions also tend to be influenced by the expertise and experiences of others (Bandura, 1989). Decisions may also be affected by feelings about the options and how we perceive others to regard the decision (Fishbein & Azjen, 1975; Janis & Mann, 1977).

There also appear to be some universal aspects of "good" decision-making processes. Matheson and Howard (1968), the founders of decision analysis theory, define a good decision as "one based on information, values, and preferences of a decision maker" (p. 12). Note the emphasis on the process of decision-making. A good decision in this context is distinguished from a good outcome, defined as "favorably regarded by a decision maker" (Matheson & Howard, 1968, p.12). These authors make the distinction that good decisions can produce favorable or unfavorable outcomes, as can bad decisions. This study will focus on understanding and improving the process of decision-making.

Janis and Mann (1977) in a review of the psychological literature on decision-making, identified seven criteria for high-quality decisions. These authors recognize that each criterion exists on a continuum, and that failure to meet any of these criteria when making a decision constitutes a shortcoming in decision-making.

The decision maker, to the best of his ability and within his information processing capabilities:

1. Thoroughly canvasses a wide range of alternative courses of action.

2. Surveys the full range of objectives to be fulfilled and the values implicated by the choice.

3. Carefully weighs whatever he knows about the costs and risks of negative consequences, as well as the positive consequences, that could flow from each alternative.

4. Intensively searches for new information relevant to further evaluation of the alternatives

5. Correctly assimilates and takes account of any new information or expert judgment to which he is exposed, even when the information or judgment does not support the course of action he initially prefers

6. Reexamines the positive and negative consequences of all known alternatives, including those originally regarded as unacceptable, before making a final choice

7. Makes detailed provisions for implementing or executing the chosen course of action, with special attention to contingency plans that might be required if various known risks were to materialize. (p. 11)

The IEP Meeting as a Decision-Making Process

Consider the IEP meeting as a decision-making process. It is influenced by factors of the law (IDEIA) as well as the relationship that exists between parents and schools. In this section, I review aspects of IDEIA pertaining to the participation of parents in IEP meetings as well as critiques of how IEP meetings currently function in relation to what is known about quality decision-making processes. More specifically, issues for parents of children with autism and diverse parents in decision-making are examined.

The law: What it says, what we do. The Individuals with Disabilities in

Education Improvement Act (IDEIA; originally Education for All Handicapped Children Act, PL 94-142), most recently reauthorized in 2004, is a federal statute that outlines the rights and responsibilities of children and youth with disabilities, their families, and schools with respect to the education of people with disabilities and by extension, their preparation for participation in society.

Part C of IDEIA (20 U.S.C. Secs 1431-1444) outlines the procedures and rights of children with disabilities or at-risk for disabilities age birth to 3 and their families. In Part C, parents are regarded as important participants in their child's evaluation and as educators of their child. A comprehensive evaluation is designed to identify the needs of the child and to be driven by needs identified by the family, placing greater emphasis on the role of parents as the primary educator and home as the educational setting. The plan for services, also known as the individualized family service plan, is designed to support the family as the context for children's development and education. As children transition from Part C to Part B, the provisions of service for children and youth ages 3-21, the role of parents becomes less intensive. The focus shifts from the family as the impetus for child development and education to the school as the primary educational setting in conjunction with the family and home. Parallel to this shift in legal language is the shift from parent as co-expert to parent and child as recipient of the service.

Parents participate in the event of their child's IEP meeting in a variety of ways. For example, they have the power to request an evaluation and participate as members of the evaluation team and IEP team. They also are entitled to prior notice of meetings and any actions proposed by the local education agency (LEA), mutually convenient scheduling,

provision of interpreters when necessary, and the opportunity to participate flexibly, via teleconference or videoconference (20 USC Sec 1414(f)). Each of these rights regards basic, physical access to the process.

Parent participation is a key principle of IDEIA, and includes several definitive rights and responsibilities. While IDEIA promotes partnership, it cannot compel it; that is left to the professionals and parents (Turnbull, Stowe & Huerta, 2007). In fact, the provisions of IDEIA in regards to the parent participation principle place an emphasis on parent accountability. The statute states:

> Over 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by…strengthening the role and *responsibility* [emphasis added] of parents and ensuring families of such children have meaningful opportunities to participate in the education of their children at school and at home (20 U.S.C. 1400(c)(5)(B)).

Recognizing that parents may need support in advocating for their child's needs, the statute establishes parent training and information centers (PTICs; 20 U.S.C. 1471) to provide education and support to families seeking to better understand their child's disability and their rights, and to communicate with the school. While these centers provide parents with valuable resources and information (Families Together Inc., 2010), there is potential disconnect when PTICs are not linked with specific LEAs. PTICs may not be familiar with local policies and resources. As is the case for the state of Kansas, there may be only one center to service an entire state (Technical Assistance Alliance, 2010).

While the statute includes a number of provisions that establish parent involvement

in giving consent for evaluations and services, it also recognizes that there are situations in which parents may not give consent, may not make their child available for evaluations, or may not respond to notices from the school of the LEA's intent to conduct an evaluation or re-evaluation. In such cases, the LEA may not pursue the initiation of services through the use of due process procedures in order to fulfill its obligation to a free appropriate public education to the child (20 U.S.C. 1414(a)(1)(D)(ii)(II)). In cases of re-evaluation, the LEA may use due process to pursue parental consent (20 U.S.C. 1414(c)(3)).

IDEIA also recognizes the "new morbidity" or the high referral rates and prevalence in special education of individuals of culturally and linguistically diverse background, low socioeconomic status, and homeless status, and the need to address these prevalence rates with a preventative approach, as well as appropriate evaluation and services (20 U.S.C. 1400(c)(10-13)).

Critiques of the IEP meeting. While the law outlines specific guidelines and requirements for the contents and proceedings of IEP meetings, the reality of parent participation may look quite different from the parameters of the statute. While parents report satisfaction with their child's special education services, they may be uneducated about their child's disability or services (Brantlinger, 1987). Parents may want to be more involved in the IEP development process, but aren't sure where to begin or how to be involved (Epstein, 2001). For parents of low socioeconomic and diverse cultural background, differences in cultural beliefs, differences between cultural majority professionals, or logistical concerns (e.g. lack of transportation or work scheduling) may impede a parent's ability to attend, much less actively participate in, a meeting about their

child's special education. (Gaitan, 2004; Harry, 1992)

Another critique of the IEP meeting includes the erroneous emphasis on paperwork and compliance with the letter of the law, rather than invoking the intentions of IDEIA. Over-emphasis on paperwork takes time away from research and education of teams to be able to thoroughly investigate options with parents. The ability to thoroughly review options and available resources are part of the seven universals of decision-making (Janis & Mann, 1977, p. 11). Critics also charge that IEPs lose their collaborative focus, instead becoming prescriptive plans that are handed to parents by professionals seeking the requisite signature (Rock, 2000). A pre-designed, formulated approach contradicts the thorough examination of options, weighing of alternatives, and detailed provisions for action that are called for in best practices for making decisions (Janis & Mann, 1977). These practices further the imbalance of power between school professionals and diverse parents. Often, there is a cultural mismatch when school professionals from an educated, higher socioeconomic status, frequently dominant culture, interact with parents of diverse culture, frequently of lower SES, who are unfamiliar with the dominant culture of the institution (Lee & Bowen, 2006). How do school professionals and parents take the opportunity that has been crafted by the intentions of the law and maximize the IEP meeting as a forum for collaboration, communication, perspective-taking, and joint decision-making that will ultimately lead to a working partnership and better outcomes for students with special needs?

Complexity of IEPs for children with autism. Autism is a disorder affecting the basic processes of communication, socialization, and behavior (DSM-IV-TR, 2000).

Students with autism may be nonverbal, engage in repetitive self-injurious behavior, and/or use aggression towards others as a means of communication. Often, there are associated intellectual disabilities. A study conducted by the CDC (Rice, 2009) indicates that approximately 1 in 110 children are diagnosed with some form of autism spectrum disorder. Since 2002, the prevalence of autism diagnoses among boys increased by 60% and among girls by 48%. Average prevalence rates overall increased by 57% (Rice, 2009). This increased prevalence means that there are and will be more students identified with autism and their families engaging with schools.

   Issues in decision-making. Parents of children with autism face decisions that are often complex, involving many issues to weigh regarding a child's behavior, communication, and education needs. One issue that creates complexity is the delay in diagnosis (Dunlap & Fox, 1999). Because the biological markers for autism are difficult to identify, diagnoses may not be made until the toddler or preschool years. Many parents report awareness of "difference" when the child is much younger – and deal with challenging behavior throughout the evaluation process (Dunlap & Fox, 1999). Once diagnosed, additional complexity results from a plethora of treatment options available, with varying levels of empirical support, cost, and personnel trained in providing such supports. Interventions available may include empirically-supported approaches, such as behavioral instructional strategies like applied behavioral analysis (ABA; Baer, Wolf & Risley, 1968) and discrete trial training (Lovaas, 1970), classroom instructional design strategies like TEACCH (Mesibov, Shea & Schopler, 2005), and communication systems such as PECS (Bondy & Frost, 1998). Alternative treatments also abound, including

dietary restrictions (e.g. glutein or casein free diets; Cornish, 2002), supplements (e.g. Vitamin B6; Pfeiffer, Norton, Nelson & Schott, 1995), or more invasive procedures such as chelation, the administration of chemical agents to remove heavy metals from the bloodstream (Sinha, Silove, & Williams, 2006). While generally this breadth of available options is desirable when making decisions, it can be overwhelming to parents new to the experience and support for them at this time is crucial (Dunlap & Fox, 1999). The wealth of information also leads to conflict when parents and school personnel disagree about the types of programming that are appropriate for the child or have incongruent expectations for the role to be filled by the other (Lilly, Reed & Wheeler, 2003).

Mandell and Novak (2005) reviewed existing literature on cultural influences on a family's interpretation and decisions regarding treatment approaches for autism. They found that beliefs about causes and the course of autism across different cultures may lead to different choices for treatment or may influence whether or not treatment is even pursued. Cultural factors impact the timing of receiving a diagnosis and treatment. Students from diverse backgrounds often receive the diagnosis later or, because of cultural differences in the parent-provider relationship, treatment relationships may not last very long (Mandell & Novak, 2005). Differences in when and how treatment is undertaken can impact long-term and educationally relevant outcomes and emphasize the importance of joining with parents to help them make choices that lead to positive outcomes for their child and family. Professionals who recognize cultural differences and are sensitive to the values that are important to families will facilitate better decisions made (Sperry, Whaley, Shaw & Brame, 1999).

Big Ideas About Big Decisions: Decision-Making and Parent Partnership Theories and Models

Conceptualizing the IEP meeting as a forum for joint decision-making that leads to partnership, it is important to understand current ideas about both aspects of the IEP meeting process. In this section, existing theories and models of decision-making are reviewed, followed by a review of theories and frameworks for parent partnership.

Decision theories and models. This section describes theories of decision-making from the psychological, economic, engineering, and medical fields. These theories/models were identified as part of a meta-analysis of tools designed to aid the decision-making process for medical patients (Durand et al., 2008). In general, there is a distinction among theories and models. A theory "satisfies two requirements: it must accurately describe a large class of observations on the basis of a model that contains only a few arbitrary elements, and it must make definite predictions about the results of future observations" (Hawking, 1988, p. 9) while models essentially describe behavior without trying to predict.

The early economic theorist Bernoulli (1954) introduced the expected utility theory, which posits that people make choices based on the expected usefulness of the outcome. Prospect theory (Kahneman & Tversky, 1979) from economics critiques expected utility theory, as it holds that decision-makers do not usually act in accordance with the propositions of utility theory. Prospect theory suggests that decision-makers assess expected gains or losses from various choices, rather than simply the utility of outcomes to help them make decisions (Kahneman & Tversky, 1979). Kahneman and Tversky (1979) suggest that people use two steps - editing and evaluation – to choose

options based on their perception of the likelihood of the associated outcome. Editing involves preliminary examination and simplification of prospects. In evaluation, edited outcomes are evaluated and the outcome of highest value is chosen. For example, consider an individual choosing between two investment options. Both options come with lengthy portfolios explaining what accounts they invest in (mutual funds, stocks or bonds) and at what rates they have been returning dividends to investors over the previous five years. Editing would involve summarizing or simplifying those portfolios - summarizing dividends as average dollar amount per year and identifying funds as risky or not risky. Evaluation would determine which Option would be most valuable based on that edited review – the highest valued investment option would be that with lowest risk and highest dividend.

Decision analysis (Matheson & Howard, 1968) is a normative theory of decision-making with roots in expected utility theory. Decision analysis uses decision trees and mathematical processes to determine probabilities of outcomes and assigns actual values to various aspects of a decision. Decision analysis utilizes three phases: deterministic, in which key factors in the decision are identified; probabilistic, estimating the probability that certain variables have for reaching various outcomes; and informational, determining whether one has accumulated enough information to make the decision, and if not, what other information is necessary to facilitate that decision.

Multiple attribute decision-making (Yoon & Hwang, 1995) refers to making preference decisions over the available alternatives that are characterized by multiple, often conflicting attributes. Using multiple attribute decision-making involves identifying

the alternatives available, and then relevant attributes of an alternative that are important to the decision-maker. For example, if one would like to come to a decision about what job to choose, one has three alternatives, Job A, Job B, or Neither. Each Job option has various attributes, such as salary, benefits, satisfaction, and stress level. The attributes are weighted by importance for each alternative. In this case, the decision-maker may weight benefits and satisfaction as most important, although the attributes of all alternatives are investigated. The decision-maker would then break down the attributes to measurable components (for benefits, the dollar amount of insurance coverage; for satisfaction, this might be quantified as a numerical rating from previous employees). Then, based on the measured attributes, the decision-maker can determine which Job option matches best with the alternatives that are most valued to him or her.

Social cognitive theory (Bandura, 1989) posits that human behavior (including decision making) is learned through observation of others. Based in the triadic theory of reciprocal determinism, social cognitive theory interprets behavior in interaction with the environment and with one's cognitions, biology, and other aspects of the self.

From the medical field, Rosenstock's (1974) health belief model delineates variables deemed influential to individuals' choices about whether or not to engage in different types of health behaviors. These factors include income and education level, ethnicity, motivation, and perceived susceptibility.

The theory of reasoned action (Fishbein & Azjen, 1975) states that a person will behave in ways predicted by his/her attitude about the behavior, as well as how s/he thinks that others will perceive him/her if the behavior is performed. This interaction of attitude

and the subjective norms individuals perceive leads to behavioral intention. Janis and
Mann (1977), in conflict theory, hold that decision-making generates stress, uncertainty,
and conflict within a choice situation, and as such, the stress inherent in the decision
process impacts the choice that is eventually made.

Turnbull and Turnbull (2009) have developed a framework known as
"wisdom-based action" that could serve as a guide for making decisions around an
individual's needs. This framework provides guidance for decision-making and also
supports the goal of partnership.

Wisdom Based Action consists of the following steps:

1. Being attuned to one's values, visions, and context (factors needed to
   consider in relationship to the child, family, local resources, and
   community).

2. Locating, evaluating, and synthesizing knowledge from experience,
   research, and policy

3. Making a balanced decision and planning next steps – judging what
   knowledge to use based on one's values, vision, and context, identifying
   whose interests should be weighed in the decision, weighing short and
   long-term consequences of the decision, and evaluating what resources are
   necessary to take the next steps.

4. Taking action – implementing next steps, learning from success and
   setback, and solving unanticipated problems (Turnbull and Turnbull, 2009).

The wisdom-based action framework enables parents to be full partners by providing

guidelines for examining all aspects of a decision and empowering parents to take "wise" steps in promoting education that creates equal opportunity, full participation, economic self-sufficiency and independent living for their son or daughter with a disability and their family.

While numerous theories about decision-making abound, literature on the use of these theories to assist in decision-making is sparse. In a review of existing decision-making tools in the medical community, Durand et al. (2008) found that only a small percentage of the tools available even mention a theoretical basis, and of those, few studies have been undertaken to evaluate the validity of such claims.

Partnership

This section will review the changing roles of parents as partners over time, the characteristics of partnership, and current models and frameworks for developing parent partnership. This section delineates general and special education approaches and highlights issues involved in partnering with parents of diverse backgrounds.

Changing roles. The role of parents in their relationships with professionals has evolved over time. One conceptualization from the early childhood special education literature describes this evolution as changing from power-over, to power-with, and most recently, power-through (Turnbull, Turbiville & Turnbull, 2000). In a "power-over" relationship, professionals exert control over parents by focusing on diagnosis and prescriptive treatment, due to a perception of the professional as the expert. Communication between parent and professional may involve extensive clinical jargon and be very directive to the parent. Resources available may be limited to what exists in the

current system, fitting the needs of the child into the pre-existing "box" of services available. This aligns with the roles of parents as the cause or source of their child's disability (Turnbull, Turnbull, Erwin & Soodak, 2006), as in some early autism research (Bettelheim, 1967; Kanner, 1949). Parents were often regarded as the "recipients" of professional decisions, without having their valuable input realized (Turnbull et al., 2006). Similarly, Christenson and Sheridan (2001) and Epstein (2001) describe traditional expectations schools have had for parents in terms of their involvement. These expectations include that parent involvement will occur on the school's terms (e.g., volunteering in classroom, helping with homework at home) and on the school's schedule (e.g., conferences and meetings during school hours). These expectations have not had the flexibility needed to create relationships with parents of diverse backgrounds (Christenson & Sheridan, 2001; Epstein, 2001).

Advocating parents responded to such perspectives through organizational development at the local and later national level to work for a wider variety of services for their children. Parents also worked for changes in local and federal laws to recognize the rights of people with disabilities and their families. Additionally, advocacy groups served as an avenue for parents to provide emotional support to one another (Turnbull et al., 2006). This response demonstrates a "power-with" approach involving more collaborative decision-making between parents and professionals, with straightforward and open communication and the utilization of resources within the current system. Parents are encouraged to activate family resources, in the form of social supports or other existing yet underutilized strengths. From the school psychology perspective, Sheridan, Warnes,

Cowan, Schemm, and Clarke (2004) conceptualize parents as providing valuable input to decisions made about their child, as well as the importance of activating social supports and other family strengths. Activating these family resources often meant parents taking on the role of teacher and implementing some form of prescribed intervention with the child at home (Turnbull et al., 2006). As parents took on this role as "educator," they also began to develop a voice and provide input into the educational decisions made about their child (Turnbull et al., 2006).

In "power-through" partnerships, parents and professionals "synergize" (Turnbull et al., 2000, p.632) with each other as well as other family members, friends, or other community members to communicate and connect with one another and create the resources that are needed to support the child and family. Parents and professionals in partnership with each other carry equal power and share collective wisdom (Turnbull et al., 2006).

Characteristics of partnership. Partnership is defined as "a relationship in which families…and professionals agree to defer to each other's judgments and expertise, as appropriate for the purpose of securing benefits for students, other family members, and professionals" (Turnbull et al., 2006, p. 110). Epstein (1995) defines shared decision-making as "… a process of partnership, of shared views and actions towards shared goals (p. 705)." Partnership has several dimensions. In a study involving over 60 focus groups and interviews with English speakers as well as non-English speaking families, Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004) identified six interrelated dimensions of partnership. First, communication must be frequent, honest,

open and coordinated. Commitment is a shared devotion to the child and family and the importance of family and child goals. The next dimension, equality, entails a sense of equity in decision-making and service implementation. Of course, skill is vital to competent service delivery from team members. Respect is another important dimension of partnership – defined as partners holding one another in high regard as demonstrated through actions and communication. Finally, trust serves as a keystone to the partnership process. This means that all partners feel assured that the other members are dependable, honest and strong (Blue-Banning et al., 2004).

Christenson and Sheridan (2001), through a review of the extant literature on systems-level partnership, identify an approach to parent-school partnerships that includes five characteristics. First, a focus on the relationship is necessary. Partners must recognize and prioritize the development of a working relationship. Second, schools and families must recognize that collaboration involves attitude as well as actions. There must be an atmosphere and climate from those involved that sets the tone for partnership. The third characteristic involves creating an approach to jointly establish an understanding of the expectations for children's development and performance. This means developing a plan for action that is mutually agreed upon and supported. Additionally, educators and families must share resources for their partnership to succeed. Each party brings strengths and needs to the relationship. These must be shared as well as supplemented for the partnership to succeed. Finally, meaningful shared roles must be established for each partner. Families and schools must understand their responsibilities and take pride in their input (Christenson & Sheridan, 2001).

Parent involvement may take different forms. Epstein (1995, 2001) identified six specific types of involvement that can guide schools and families in developing partnerships. The first type is providing parenting assistance, or working with parents to establish a home environment to support children as students. To enhance this form of involvement, partners appreciate cultural differences and individual child and family characteristics. It also means sharing clear and useful information on helping children at home. Next, communication between home and school follows two-way channels, occurs frequently, is clear, and is available in the parents' language. When involvement takes the form of volunteering, parents are recruited widely and for a variety of jobs occurring on a variety of timeframes to allow for as many opportunities as possible. Organization of such activities can match talent to need and enhance opportunities for recognition and appreciation. Involvement can also occur through learning at home, by engaging in interactive homework sessions and gaining parent input on curriculum-related decisions. Yet another type of involvement takes the form of decision-making. This decision-making occurs in specific situations applicable to their child's individual situation. It also means including parents as representatives for school councils and leadership teams. Collaborating with the community means identifying available resources. These resources can then be integrated with school programs and family practices to enhance student learning (Epstein, 2001).

Across models, there is an emphasis on communication and mutual valuation of partners in the relationship. Parents are increasingly recognized for the valuable input they have to offer. Communication must be open and honest. Partners have individual

responsibilities. There is increased emphasis on understanding the context of the relationship and moving away from the traditional roles and expectations of parents and professionals towards synergy and thinking flexibly about partnerships.

   Family-Centered Positive Psychology. In the school psychology literature, a model known as Family-Centered Positive Psychology (FCPP; Sheridan et al., 2004) has emerged and is defined as "a framework for working with children and families that promotes strengths and capacity building within individuals and systems, rather than focusing solely on the resolution of problems or remediation of deficiencies" (p. 7). FCPP is based in the following five key principles:

1. Recognizing the importance of process and outcomes.

2. Using existing family capacities and strengths to access and mobilize resources.

3. Focusing on family-identified rather than professional-identified needs.

4. Promoting acquisition of new skills and competencies through specific types of helping behaviors

5. Emphasizing and strengthening existing social supports and networks.

While these principles are designed to guide all aspects of school psychologists' professional practices, one specific way the model is implemented is through Conjoint-Behavioral Consultation (CBC; Sheridan & Kratochwill, 1992). CBC is a problem-solving process in which parents and teachers come together with school-based consultants to resolve behavioral and/or academic concerns for a student. This approach may be used in conjunction with general education intervention, during the IEP review and development process, or as part of a nondiscriminatory evaluation. CBC has been shown to

improve outcomes academically and behaviorally for students whose families and teachers participated (Garbacz, Woods et al., 2008). FCPP, and thus CBC, rely on professional facilitation of the process.

General best practices. Recommendations from the National Association of School Psychologists for best practices in partnering with parents for education decision-making include sharing information and promoting education, encouraging parent advocacy, providing support to parents, facilitating healthy family functioning, individualizing services, and maintaining aspects of general best practices in communicating with parents (e.g., avoiding use of jargon, flexible scheduling, addressing correspondence to both parents, and establishing a relationship before there is a crisis; Fish, 2002).

Partnership models and frameworks specific to individuals with disabilities. Dunst, Trivette and Deal (1994) in their work with families of children in early childhood special education, describe partnerships as empowering processes. By being proactive in approaches, professional help-givers offer support and create enabling experiences that promote competence in parents. Through these behaviors, professionals empower parents by enhancing their feelings of control and contribution in the process. Dunst et al. (1994) suggest that the active participation that is expected of parents promotes behaviors encouraging self-efficacy and control.

One approach to future planning and decision-making is known as person-centered planning (O'Brien & O'Brien, 2000). These approaches form a team of individuals interested in supporting a focus individual's goals and visions for the future.

Person-centered planning involves family engagement with community by activating friends, acquaintances and support providers as team members. Person-centered planning also takes the form of school-based approaches.

Community-based approaches. Group Action Planning (GAP) builds a network of friends, professionals, family, and community members who are committed to an individual with a disability and to helping that individual achieve his or her goals (Turnbull & Turnbull, 1996). There are two fundamental characteristics to GAP. First, GAPs create a context in which a person with a disability is surrounded by and connected to people who care about him or her. Second, GAPs promote dynamic problem solving that activates these connections to create solutions and guide action. GAP components include (a) inviting support, (b) creating connections, (c) envisioning great expectations, (d) solving problems, and (e) celebrating success (Turnbull & Turnbull, 1996).

School-based models and approaches. MAP (Forest & Pearpoint, 1992) is a collaborative process that brings together key stakeholders in an individual's life in order to develop a plan to incorporate the person into the classroom setting. The MAP process is typically facilitated by two people intimately familiar with its procedure. One person guides the discussion by utilizing eight key questions, while the other records comments and ideas from the meeting, creating a visual representation or "map" for all to see and use in developing the next steps to achieve the MAP team goals. Based on the eight guiding questions that collect information about a person's background, interests, strengths, desires, fears, and goals, a concrete action plan is formed.

Giangreco et al. (1998) developed the COACH (Choosing Outcomes and

Accommodations for Children) Model, a guide for decision-making designed to enhance

parent participation in the IEP process. The COACH model espouses six major principles:

1. Pursuing valued life outcomes is the goal of all educational practices.

2. Families are the keystone to educational planning.

3. Collaborative teamwork is essential to quality educational outcomes.

4. Coordination among service providers is essential to appropriate education.

5. The problem-solving process improves the effectiveness of educational

   planning.

6. Special education is a service, not a place. (Giangreco et al., 1993, p.109)

Based upon these six principles, the COACH model outlines a series of interview and

decision-making steps to enhance collaboration among families and professionals. A

particular emphasis is placed on the Family Interview, in which parents outline priority life

outcomes for their child, coordinate those outcomes with curricular activities, and

prioritize among and across curricular activities to identify IEP targets prior to meeting

with the IEP team. Constant questioning and problem-solving strategies are used

throughout the process with all team members, encouraging "sensible advocacy" by

parents (Giangreco, Whiteford, Whiteford, & Doyle, 1998, p. 396).

In a national expert review of COACH, preliminary results from two studies,

including professors, practitioners, and parents, supports the validation of COACH as a

tool that follows best practices in educational decision-making and that is socially valid.

(Giangreco, Cloninger, Dennis & Edelman, 1993). Another study, conducted by

COACH's developers, focused on students who had hearing and/or visual impairments. It

evaluated how people use COACH and the ways in which educational programming, parent-professional relationships and students' valued life outcomes were affected based on COACH's use (Giangreco, Edelman, Dennis & Cloninger, 1995). Respondents reported that COACH led to shorter, more focused educational plans; enhanced the relationship between parents and professionals; and raised expectations; new opportunities, and different outcomes for children (Giangreco, Edelman, et al., 1995).

While this approach makes strides in promoting parent engagement in the IEP development process, there are also some limitations and recommendations for future work. The focus of development of COACH has been with families of children with multiple and severe disabilities, and students with deaf-blindness. There has not been a focus on the specific decision-making needs of families of children with other disabilities such as autism (Giangreco, Whiteford, Whiteford, & Doyle, 1998). Also, while attempts have been made to include parents of diverse backgrounds, more work is needed to develop the COACH tool to be culturally sensitive (Giangreco et al., 1993).

Partnering with Parents from Diverse Cultural, Linguistic, and Socioeconomic Backgrounds

Establishing partnership with parents is vital, especially with families of students from low SES and diverse racial/ethnic and linguistic backgrounds. IDEIA recognizes this fact in its discussion of the "new morbidity" or the increased prevalence of disability in students from such backgrounds [(20 USD Sec 1400 (c)(10-12)]. In light of the new morbidity, it is increasingly important to engage with parents of "at-risk" children, to have full understanding of parents' perceptions of their child's abilities, and to provide support

in areas identified by the family.

While parents from diverse backgrounds seek to participate in their child's special education, they often lack the knowledge of how to do so (Epstein, 2001). In interviews with 35 parents of low SES, Brantlinger (1987) found that while parents reported satisfaction with their child's services, they frequently could not identify the type of program in which their child was participating (e.g., inclusive classroom, resource room). Gaitan (2004) identified certain lifestyle variables that may influence when and how Latino parents become involved – citing such factors as work schedules, family constellation, and language barriers as reasons parents are unable to participate in more traditional school activities such as volunteering in a classroom, attending Parents' Night, or accompanying their child on a field trip. Another study, conducted across 39 neighborhoods in Baltimore with predominantly African-American families, found that lower neighborhood SES was associated with lower problem-solving ability. The authors suggest this different capability may have some predictive influence on academic achievement for children of lower SES (Caughy & O'Campo, 2006).

Although parents from diverse racial/ethnic and SES backgrounds may have difficulty forming partnerships with school personnel, it does not mean that they are not holding high expectations for their children's future. Gaitan (2004) notes that Latino parents report highly valuing education and its benefits. Blue-Banning, Turnbull and Pereira (2002) conducted interviews with Latino parents to discern their visions for their children's futures. These visions included acceptance for their children, a comfortable living situation (although this vision diverged as to whether parents sought to have their

son or daughter living in the family home or independently), and enhanced employment and leisure experiences. In a survey of parents of diverse background in urban Title 1 schools, parents reported that while they had not been invited by the school to become involved, they would like to be. Additionally, parents reported a desire for information on how to help their children at home with their schoolwork and their unique personal talents (Dauber & Epstein, 1993).

This body of research establishes that the educational system must do more to engage with parents and empower them to participate in decisions made about their child's education. This means thinking flexibly and collaboratively while talking with diverse parents to understand how to better partner.

Decision Aids

Recent work in the medical community enhances the participation of patients in their care decisions using what are known as decision aids (Jacobson & Connor, 1999, 2006). Decision aids are "evidence-based tools designed to prepare clients to participate in making specific and deliberated choice among healthcare options in ways they prefer" (O'Connor, Bennett et al., 2009, p. 6). Over 200 different forms of decision aids are estimated to be in use around the world and vary from simple checklists, to video aids, and even a Facebook application (e.g. iShould; Ottawa Hospital Research Institute, 2010). Decision aids are rooted in the concept of informed choice – that patients who are educated about their options make better decisions and are more satisfied with the outcome (Jepson, Hewlson, Thompson & Weller, 2007).

Characteristics of decision aids. At a minimum, medical decision aids provide

information on options and outcomes relevant to a person's health status, and include methods to clarify patients' values (O'Connor, Bennett et al., 2009). They may also include (a) information about a person's disease or condition, (b) costs associated with treatment options, (c) the probabilities of outcomes tailored to personal risk factors, (d) explicit exercises to assist patients in clarifying values, (e) information about others' opinions, (f) guidance/coaching in the steps in decision-making, or (g) a personalized recommendation based on a patient's clinical characteristics and expressed preferences (O'Connor, Bennett et al. 2009). Decision aids may be specific to a condition (e.g. bowel cancer, other cancer types, health screenings; Barratt, Trevena, Davey & McCaffery, 2004; O'Connor et al., 2004) as well as specific to particular populations (e.g. low literacy; Smith et al., 2009).

The International Patient Decision Aids Standards (O'Connor et al., 2007) provide criteria for gauging the quality of decision aids. These criteria include: (a) using a systematic development process, (b) providing information about options, (c) presenting probabilities related to different treatment choices, (d) encouraging patients to clarify and express values, (e) using patient stories to communicate about treatment options, (f) guiding/coaching in deliberation and communication, (g) disclosing conflicts of interest, (h) delivering patient decision aids on the internet, (i) balancing presentation of options, (j) using plain language, (k) basing information on up-to-date scientific evidence, (l) establishing effectiveness.

Efficacy. O'Connor, Bennett et al. (2009) conducted a meta-analysis of 55 randomized control trials of 51 separate decision aids conducted in seven different countries. Outcomes were evaluated related to aspects of the decision including (a)

knowledge, (b) decisional conflict, (c) communication between patient-practitioner, (d) participation in decision-making, (e) satisfaction, (f) choosing and adhering to an option. Additionally, they evaluated health outcomes such as (a) general health, (b) physical function, (c) social function, (d) mental function, (e) role function, (f) bodily pain, (g) emotional role, (h) energy/vitality, (i) functional status, (j) health utilities, and (k) condition-specific outcomes. They also examined the effects of decision aids on mental health outcomes such as (a) depression, (b) anxiety, (c) decisional regret, and (d) confidence. Monetary (i.e. cost of materials and personnel to administer decision aids) and time resources were also examined as systemic effects. Comparisons were made between use of a decision aid and a control, non-use condition as well as a comparison of detailed versus simpler decision aids (O'Connor, Bennett et al., 2009).

Decision aids were found to improve patients' knowledge about options and to reduce conflict in a decision in terms of feeling uninformed or unclear about personal values. Use of a decision aid also decreased the proportion of patients who remained undecided and stimulated people to take more active roles in their care decisions. More detailed decision aids appeared to have marginally increased patient knowledge in comparison to less detailed formats, but appear to have been more informative as far as risk perception and developing congruence between values and treatment option (O'Connor, Bennett et al., 2009).

Results were variable as to the degree to which the use of decision aids led to a preference for particular options. In this meta-analysis, preferences for more invasive or aggressive procedures (e.g. elective surgery, hormone replacement therapy) were

decreased in favor of more conservative options. Decision aids were not shown to have a significant positive effect on satisfaction, anxiety or other quality of life variables. The authors determined that there were too few studies reviewed to determine effect of decision aids on adherence to the chosen option, cost or resource use (O'Connor, Bennett et al., 2009).

The main effects of decision aids can be summarized as increasing knowledge of options and their outcomes as well as more accurate perceptions of probable outcomes. They also facilitate increased patient comfort with treatment decisions, and increase patient involvement in decision-making. These factors are important in that prior to use of decision aids, patients' measured knowledge levels were inadequate to make informed decisions. In fact, patients who were informed about probable outcomes and risks often changed their preferences after using a decision aid (O'Connor, Bennett et al., 2009).

Examples. The Ottawa Hospital Research Institute Decision Aid Library Inventory (2009) currently lists 278 decision aid tools. Topics range from infertility treatments, to end of life care, to tennis elbow treatment options. Additionally, the Substance Abuse and Mental Health Services Administration (SAMHSA) has promoted a movement known as shared decision making, which incorporates the use of decision-making tools in empowering clients to make informed treatment choices (Deegan, Rapp, Holder & Riefer, 2008).

Educational tools: A review. Existing educational decision-making tools were identified using KU Libraries multiple database search (PsychInfo, ERIC, Academic Search Premier) and the following search terms: Decision-making tools special education (subject).

Titles were selected based on timeliness (published within the last 20 years), relevance to the topic of facilitating parent decision-making and the possibility that pre-existing aids were discussed. Based on these criteria, six articles were selected from an initial pool of 59 titles from ERIC and 15 articles from PsychInfo. These article abstracts were then reviewed for potential tools used to facilitate parent partnership in IEP decision-making. From these six article abstracts, two tools were identified that appeared to meet the definition of a decision aid according to O'Connor, Bennett et al (2009): "evidence-based tools designed to prepare clients to participate in making specific and deliberate choice among healthcare options in ways they prefer" (p. 6). The tools included were: Choosing Outcomes and Accommodations for Children, 2nd Edition (COACH; Giangreco et al., 1998) and the Transition Planning Inventory – Updated Version (TPI-UV; Clark & Patton, 2006). While further searches identified several books as "guides" for approaching special education and parents' work with their school teams, it was determined that more formal, published and reviewed tools would be included and that more general "guidebooks" would not be included in the review. Based on consultation with one test author, an additional tool was included in the review, the TEACCH Transition Assessment Profile, Second Edition (TTAP; Mesibov, Thomas, Chapman, & Schopler, 2007), for a total of 3 tools.

Review criteria utilized the quality indicator domains from the International Patient Decision Aids Standards (IPDAS; O'Connor et al., 2007). The IPDAS identify 12 domains for the evaluation of decision aids, listed in Table 1. The three identified formal decision-making tools were reviewed utilizing these criteria. It should be noted that the

domain regarding delivery of the decision aid on the internet was deemed not applicable

for all 3 tools, since none of them were available on the internet. While none of the tools are

available on the internet, the TPI does provide a computer version of its tool available on

CD-ROM.

The TPI-UV (Clark & Patton, 2006) is an assessment tool designed to aid in

transition planning for children with disabilities. The tool includes questionnaires to be

completed by the student, caregivers, and school personnel to determine strengths and

areas in need of growth when preparing for transition from school to work and developing

Individualized Education Plans (IEPs). The TPI-UV performed highest in its use of a

systematic development process, but was lacking in its presentation of probable outcomes,

use of client stories as part of the tool, guiding and coaching in deliberation,

communication disclosing conflicts of interest, and establishing effectiveness.

COACH (Giangreco, et al., 1998), reviewed earlier as a model for partnership, is

also accompanied by a tool designed to be used by school teams to facilitate

decision-making around IEP development and related services provision. It incorporates

input from a Family Interview and a series of brainstorming and prioritization activities

across five valued life outcomes to develop meaningful IEP goals and determine necessary

related services to meet those goals. COACH received the highest ratings across all

domains. This may be due to the fact that it was the only tool explicitly identified as aiming

to facilitate the decision-making process. COACH used a systematic development process,

used guiding and coaching in deliberation and communication, and establishing

effectiveness. However, it lacked in the domains of presenting probabilities, use of patient

stories, disclosing conflicts of interest for aid developers, and balancing the presentation of options.

The TTAP (Mesibov, Thomas, Chapman, & Shopler, 2007) is also a tool used as part of transition assessment, geared specifically for young people with autism. It includes a series of activities an assessor may use to evaluate an individual's work-related skills in a direct observation format, or through reports from school and home. The TTAP also fell short in the domains mentioned regarding the previous two tools; in addition, it received the lowest score for using a systematic development process.

Across the tools included in this review, there were deficits in the tools' focus on identifying client values, presenting probabilities related to choice options, balancing the presentation of positive and negative options, and the use of patient stories in the decision aid tool itself. All three tools focused on the professionals who would be administering the tool, and to a lesser degree or not at all on the decision-making process for the parent. Only COACH provided any sort of coaching or guidance for parents in deliberating and communicating about their values or aspects of their decision.

Summary

Decision-making is a universal process that occurs constantly in life. Certain universal characteristics include surveying available information, considering the impacts of the decision on important people over the short and long term, and taking into account what is important to the decision-maker at the current time and for the future.

Parent participation in educational decision-making is recognized as important by special education law and by the special education and school psychology literature.

Partnership in decision-making is especially important for parents of diverse culture and

SES, who participate at lower rates, and for whom participation and partnership may mean

different things. Within that population, partnering with parents of children with autism is a

priority, due to the complex effects of autism on children's communication, socialization,

and behavior, a plethora of available resources and interventions, and negotiation of those

resources and roles of schools with the expectations of parents. Decisions that diverse

parents must make are often complex and their priorities may be different than those of the

professionals with whom they work (Dunlap & Fox, 1999; Mandell & Novak, 2005). Best

practices for developing partnerships between parents and school professionals should

include frequent collaboration and communication, a trusting relationship, and co-equal

roles. Combining this partnership with high quality decision processes should lead to

exceptional educational outcomes for children. However, aspects of the law, and how IEP

meetings currently operate create barriers to optimal joint decision-making (Rock, 2000;

Sperry, Whaley, Shaw & Brame, 1999).

One method that has been used in the field of medicine, and to a lesser degree in

education, is the use of decision-making aids to enhance joint decision-making between

patients and providers or between parents and educational professionals. These aids have

been shown to increase patient knowledge about the aspects of their decision, as well as

increase parental participation and perception of their relationship with their school team.

However, when these tools are reviewed, few posit a theoretical basis, and when

educational decision tools are evaluated using an international quality criteria checklist,

they fall short in addressing specific populations and encouraging parents to identify their

values and in a process for making decisions, and focus on professionals as the administrator of the tool.

While there is a wealth of information on decision processes, and recommendations for how best to make decisions, more work is needed to understand the decision-making processes of diverse parents of children with autism. Using this understanding, a decision-making tool would facilitate decision-making, lead to better outcomes for students and enhance partnerships between parents and educators.

Research Questions

1. What factors (environmental, behavioral, relational) influence the decision-making process of diverse parents of elementary-aged children with autism?

2. What are the decision-making needs of diverse parents of elementary-aged children with autism?

3. What are the necessary components of a decision aid for diverse parents of elementary-aged children with autism?

Chapter 3

Method

Design Research

Because this study investigated the development of an intervention, with the ultimate goal of enhanced parental decision-making capacity, design research seems an appropriate methodology. The exploratory nature of this work lends itself well to a qualitative approach.

Design research is described as "a series of approaches, with the intent of producing new theories, artifacts, and practices that account for and potentially impact learning and teaching in naturalistic settings" (Barab & Squire, 2004, p.2). This relatively new approach to research considers education research akin to engineering. Middleton, Gorard, Taylor, and Bannan-Ritland (2008) describe the activities associated with this type of research as a series of subtle yet complex interactions between designer and contextual constraints. In design research, an innovation or artifact is developed which embodies a functional need identified through a coherent and replicable chain of theory-based reasoning (Middleton et al., 2008).

In the current high-stakes competition for grants to understand "What Works" in education, too often there is a rush to create an innovation without thoroughly pilot-testing and examining its function in relation to its hypothesized effects (Kelly, 2006). One way to ensure an increased likelihood of effect in a randomized control trial (RCT) is to develop interventions through a series of rigorous, iterative trials, obtaining feedback with each attempt and incorporating that feedback into successive versions of the tool. Some

researchers in the field consider design research to be important preliminary steps that could be added to the "What Works" Model to ensure high-quality innovations with increased likelihood of effectiveness in RCTs (Kelly, 2006).

Design research utilizes qualitative feedback from prototype testing to enhance the development of an innovation (Kelly, 2006). In this way, it incorporates qualitative techniques into existing quantitative methodology. Design research capitalizes on the strengths of both methods, without sacrificing methodological rigor. By being grounded in theory, rigorous in data collection, purposive in its sampling process, and contextual in its analysis, design research leads to an understanding of a transportable innovation that extends beyond significance level (van den Akker, Gravemeijer, McKenney, & Nieveen, 2006).

Design research moves from asking the question, *does* an intervention work, to *how or why* does it work. It aims to explain innovations' effectiveness or ineffectiveness theoretically, to re-engineer innovations when possible, and to enhance the science of design itself. Design research is often a participatory process, involving stakeholders in design, implementation, and data collection. (Kelly, Baek, Lesh, & Bannan-Ritland, 2008)

Design research has multiple phases – design (also known as informed exploration), development (enactment), evaluation (this can be at local or broad levels, or both). The design or exploration phase begins with a thorough review of the literature and an understanding of the underlying theory that will ground the innovation as well as the needs and characteristics of the audience the tool hopes to reach. The development or enactment phase involves operationalizing what has been found in the literature into an

intervention based in the identified theory (Bannan-Ritland & Baek, 2008). The pilot-testing or evaluation phase involves implementing the innovation with a small sample and gathering valuable qualitative and quantitative data on the implementation and impact of the innovation. These data inform future iterations of the innovation and fine-tune it in order to understand and maximize its effect in later, larger trials. Some researchers conceptualize these large-scale trials as a fourth phase in the process (Bannan-Ritland, 2003; Bannan-Ritland & Baek, 2008; Reinking & Bradley, 2008).

When undertaking design research, one begins with what are known as "first principles" derived from experience, review of the literature, and goals of the study (Brown, 1992). For this study, the first principles were as follows:

1. Partnership with parents is key to guaranteeing quality outcomes for students in special education, especially students with autism.

2. Parents (particularly those of culturally and/or socioeconomically diverse background) need resources and support to empower their participation in their students' special education experience.

3. A decision aid developed with and for parents of diverse ethnic and SES background will enhance parents' experiences working with their IEP team.

The purpose of this study was to design a high quality decision aid tool based in grounded theory through the use of exploratory qualitative methods.

Research Questions

The research questions guiding this study were:

1. What factors (environmental, behavioral, relational) influence the

decision-making of diverse parents of elementary-aged children with autism?

2. What are the decision-making needs of diverse parents of elementary-aged children with autism?

3. What are the necessary components of a decision aid for diverse parents of elementary-aged children with autism?

This study sought to understand the factors that influence parents' decisions, and design a tool that organizes a decision-making process for parents of children with autism. This understanding and tool were designed in partnership with parents who have children with autism and who have experience working with education professionals.

Research Site

This study took place in the Kansas City, KS public schools, an urban school district diverse in its socioeconomic and racial/ethnic composition. This district not only has a high population of parents experiencing issues discussed earlier, it is also the district in which I worked as a school psychologist during the course of this study. Special education teachers, school social workers, and school psychologists assisted in the identification of parents and other educators who participated in the study as focus group members, Advisory Board members, or both.

Participants

Purposive sampling was used to select participants, as recommended by Maxwell (2005). Sampling sought to engage parents who have had a variety of experiences, positive and negative, with their IEP teams in order to identify confirming and disconfirming cases of developing grounded theory. Diverse parents of elementary-aged children with autism

were the focus of this study because of the need for a decision aid tool tailored to the specific decision-making needs of this group of parents.

Participants were recruited via notes sent home informing them of the opportunity to participate. Parents of approximately 93 students were contacted via flyers sent home with students. Two parents (2%) contacted the researcher via these flyers. School psychologists and special education teachers working in Kansas City, KS public schools were also asked to nominate parents with whom they work who would fulfill participant criteria (reputational sampling). Based on those nominations, eight families were contacted, of those families, 50% (4) had a parent who agreed to participate. See Table 2 for a description of parent characteristics. All parents who agreed to participate were mothers. All of the mothers had children who were students in grades kindergarten through 5th grade and received special education services under the eligibility category of autism in the Kansas City, KS public school district. Two children were in 2nd grade, with one student each in kindergarten, 1st, and 5th grades. Parents who participated approximated the demographic composition of the Kansas City, KS public schools: approximately 40% African American, 40% Latino, 15% white, and 5% other ethnic groups. Of the five mothers participating in the focus groups, two were African American (40%), two were Latino (40%) and one was white (20%).

Table 2.

Characteristics of Participating Parents.

Parent Initial	Gender	Ethnicity	Child Grade	Number of Years with IEP	Number of Years in Current School District
N	Female	African American	2nd	6	1.5
K	Female	Latino	Kindergarten	3	3
Te	Female	White	1st	3	<1
Ta	Female	African American	5th	7	2
L	Female	Latino	2nd	4.5	4.5

Professionals were recruited for participation via email, personal contact, and presentation at professional development meetings for school psychologists and school social workers. Staff with varying years of work experience and varying training experiences (e.g. teachers, school psychologists, administrators, social workers) were recruited to provide a balanced representation of professionals with whom parents come in contact. Selection of a small, targeted group of staff with specific background experiences provided insight into the specific phenomenon that is the focus of this study (see Lilly, Reed & Wheeler, 2003). See Table 3 for a further description of characteristics of professional participants. Five professionals agreed to participate, all of whom were White and female. One participant was an elementary school principal, two participants were school social workers, and two were special education teachers. Of the special education teachers, one teacher focused specifically on students with autism with more intensive support needs, while the other teacher worked with a wider range of students, including

some with autism and some with other types of disabilities. Years working with the school district ranged from approximately a year and a half to 25 years. Number of students worked with for each professional ranged from approximately four students to over 100. One professional also disclosed that she had some familial experience with autism spectrum disorder.

Table 3.

Characteristics of Participating Professionals.

Professional Initial	Gender	Ethnicity	Job Title	Number of Students with Autism Served	Number of Years With Current School District
D	Female	White	Special Education Teacher	4	5
Ch	Female	White	School Social Worker	60	1.5
K	Female	White	Special Education Teacher	12	3
Ca	Female	White	School Social Worker	>100	25
Co	Female	White	Principal	50	5

From those parent and professional focus group participants, four parents and three professionals served on the Advisory Board. Advisory Board members were willing to continue participating and were interested in designing a decision aid tool.

Proper authorization and approval was granted from both the University of Kansas

- Lawrence Human Subjects Committee and the school district's Institutional Review Board prior to undertaking the study (see Appendix D). Parents and professionals were informed of the voluntary nature of participation and their right to discontinue participation at any time. Consent forms were signed by parents and professionals to indicate their willingness to participate (see Appendix C).

Parents participated in focus groups of 5 participants. Group formats encourage individuals to build upon ideas from one another, with minimal influence from a moderator (Madriz, 2000; Morgan, 1998) Teachers and other school staff who work with elementary-aged students with autism were also invited to participate in focus groups utilizing similar guiding questions, but adapted for use with teachers/school staff. Three school-based professionals agreed to participate on the Advisory Board, based on their interest in the design of a decision aid tool and willingness to share further experiences and insight into decision-making for diverse parents of children with autism.

Procedure

Design research typically undergoes multiple phases (Bannan-Ritland, 2003; Gravemeijer & Cobb, 2006). A self-described "meta-model" (Bannan-Ritland, 2003, p. 24) for the design research process is called the Integrative Learning Design Framework, (ILDF; Bannan-Ritland, 2003). The ILDF outlines design research as it moves through the phases of exploration, enactment, evaluation for local impact, and evaluation for broader impact. The informed exploration phase focuses on understanding the needs of stakeholders, surveying the literature, developing theory, and characterizing the audience for the innovation. In the enactment phase, a preliminary version of an intervention is

designed and revised, with multiple iterations of the tool likely as it is repeatedly reviewed and revised. This study focuses on the understanding of the underlying theory of decision support needs, and then design of a decision aid tool prototype. However, it does not yet test the tool's use.

Design/Exploration Phase: Focus Group #1 and Selection of Parent Advisory Board members. Parents of diverse ethnic and socioeconomic backgrounds who are also parents of children with autism participated as members of the focus groups. The purpose of the focus groups was to determine parents' specific questions and concerns related to the decision-making process for their child's special education, as well as outcomes that are important to them in terms of their child's academic and behavior skills. This is similar to the method used by Lilly, Reed and Wheeler (2003), who interviewed small groups of parents of children with autism to understand their "lived experience" (p. 33) in working with their school teams.

In focus groups, parent participants were asked key questions around their current concerns and needs for making decisions in partnership with education professionals. Focus group methods followed guidelines from Krueger (1998). As qualitative analysis progressed, focus groups met again to answer clarifying questions aimed at developing clear and cohesive codes and concepts (Strauss & Corbin, 1996).

General interview questions were used, meant to guide discussion without being leading, as suggested by Maxwell (2005). General questions asked participants about decision-making, challenges parents face in making decisions and sought suggestions for the necessary components for facilitating decisions through the use of an aid. Follow-up

questions then probed into more specific details of the team's decision-making process.

Questions utilized in focus groups were guided by the research questions of this study, decision-making criteria identified by Janis and Mann (1977), as well as decision-aid needs assessment literature (Jacobson & Connor, 1999, updated 2006). Guiding questions for parents and school professionals included the following (follow up questions are enumerated below each guiding question). These questions were reviewed for clarity of content with parent reviewers prior to their use with focus groups.

1. What educational decisions do you have to make in IEP meetings?

    a. What decisions do you find yourself making about goals, objectives and placement for your child?

    b. How do you think through those decisions?

    c. What makes it easier or harder to make a decision? Who helps you make a decision? What information do you need to help you decide?

2. What factors do you consider when making your decision?

    a. How do your values impact decisions that you make?

    b. What visions do you have for your child's future?

    c. What short and long-term effects do you consider in making decisions?

    d. How do other factors in your environment (family, home, community) impact your decisions?

3. What are your preferences for how you receive decision-making support?

    a. What do you wish you knew more about? What is confusing about these decisions and meetings?

b. If someone gave you a road-map for making decisions, what do you
think would be on it? How would it look? How would it work?

After moving through guiding questions, research summaries regarding existing findings of parent decision-making in IEP meetings were reviewed with parents and professionals, asking for their responses or reactions to the existing research.

Responses from these interviews were analyzed and coded for qualitative themes that were used to guide decision aid development. Member checks were conducted after identifying initial themes, to confirm their interpretation.

Design/Exploration Phase: Focus Group #2 and Selection of Professional Advisory Board members. Teachers, related service providers, and administrators who work with diverse parents of children with autism were also recruited to participate in focus groups. Staff responded to questions parallel to those asked of parents, and framed to answer the questions of what parents need to help them make decisions and partner with their team. At the end of the meeting, professionals were presented with summaries of existing IEP decision-making research as well as preliminary findings from the initial parent focus group, and were asked for their reaction to this research. At this meeting, professionals were selected to participate as Advisory Board members.

Design/Exploration Phase: Focus Group #2 meets again. A follow up focus group was conducted with school professionals to clarify emerging codes, categories, and themes. At this meeting, a draft model of the decision-making process that emerged based on parent and professional focus groups was shared with focus group participants. Participants were asked if the findings appear to be representative of previous discussion, if

anything important had been omitted, and if there were any points that should be added, utilizing the opportunity to conduct member checks (Blue-Banning, Turnbull & Pereira, 2002; Strauss & Corbin, 1996). Member checks involve presenting a summary of the findings to participants for their review. This process gives participants the opportunity to express whether they perceive the findings as accurate (Creswell, 2007). Based on feedback and input from professionals, the model was revised to better clarify decision-making components and organization of themes.

Design/Exploration Phase: Focus Group #1 meets again. At this second meeting with parent participants, I conducted a member check, reviewing themes with parent participants and obtaining their feedback and their impressions of the interpretations I made based on the emerging themes, presented as a draft model that incorporated both parent and professional feedback. Again, findings were checked with participants to determine if the findings appeared to be representative, if any key information was omitted, and if there were any items that should be added (Blue-Banning et al., 2002). Upon clarifying the model both sets of focus groups (parents and professionals) were concluded. The Advisory Board then began holding meetings, the content of which is described in the next section.

Design/Exploration Phase: Model presentation and decision aid design with Advisory Board. As a part of the initial meeting with the Advisory Board, a model based on themes identified through focus groups and interviews was reviewed. The framework for decision-making criteria as outlined by Janis and Mann (1977) was presented to the Advisory Board to guide the process of decision-aid development. The framework was

adapted to be meaningful to the Advisory Board partners and congruent with the authentic

grounded theory. The quality criteria framework developed by the IPDAS (see Table 1)

was also shared with the Advisory Board to ensure that criteria have been reached for a

high quality decision aid tool. Due to low parent attendance (only one parent attended this

meeting), cooperative brainstorming was not conducted until the following Advisory

Board meeting.

Design/Exploration and Early Enactment Phase: Further decision aid design

with Advisory Board. Another Advisory Board meeting was held with 4 parents and 3

professionals from the focus group. At this meeting, content from the previous Advisory

Board meeting was shared with those who were not present previously. Cooperatively,

concepts for the decision aid were developed at this meeting, identifying the medium of the

aid (video, computer, brochure, checklist, or other) and its key components.

An additional Advisory Board meeting was held to discuss further iteration of the

aid and to obtain feedback on its design. At this meeting, only two parent Advisory Board

members attended due to unexpected scheduling difficulties. Advisory Board members

recommended contacting other professionals in the district to generate additional content

including terms to know and common questions parents may ask during an IEP meeting.

Using available Advisory Board feedback, and review using the IPDAS criteria, the tool

was reviewed and consensus was reached on its social and content validity by professional

participants and the parents in attendance.

To obtain further parent Advisory Board member feedback, an additional meeting

was held with parents from the Advisory Board, as well as to obtain input from parents on

their participation in the study. Two parents attended this meeting and consensus was reached on the tool's ability to capture all relevant aspects of the model, and adequate acceptability (utility and usability). The model and tool will be presented to my dissertation committee for expert review. These steps are congruent with those followed by Smith et al. (2009) in the development of a decision aid for adults with lower literacy.

Data Analysis

Qualitative research is an iterative and interactive process between the researcher and the data (Maxwell, 2005). I analyzed transcripts and notes from focus groups and interviews, meetings with the Advisory Board, and reflective memos to identify themes around the types of decisions that parents must make and the information and resources necessary to help them make decisions about their child's special education. Creswell (2007) outlines six steps in qualitative analysis: (a) organizing and preparing the data, (b) obtaining a general sense of the data, (c) using a coding process to conduct a detailed analysis, (d) using the coding process to develop a description of the phenomenon (e.g. themes and a theoretical model), (e) establish how findings will be presented, and (f) make an interpretation about the data. It should be noted that while this process is outlined as linear, it is iterative and reflective and was repeated multiple times throughout the study.

Organizing and preparing the data. Focus groups occurred in a staggered fashion, at approximately four week intervals, to allow time for transcription and analysis. There was a significant delay between the first and second meetings of Focus Group #2 (Professionals) due to weather issues. This meeting occurred at approximately an 8 week interval. All focus groups and Advisory Board meetings were video- and audio-recorded

and converted to transcripts, which the researcher read for verification. The qualitative

software program Atlas.ti v.6 (Scientific Software, 2010) was used to organize, manage,

and analyze qualitative data.

Qualitative data collection and analysis was ongoing. From member checks with

focus groups, the model was revised to accurately reflect emerging themes. Based on

feedback from the advisory board, the decision aid was adjusted and altered to fine-tune its

utility and functionality. Debrief notes from focus groups and Advisory Board meetings

facilitated interpretation of the comments shared during meetings and focus groups. I kept

memos regarding themes emerging from focus groups and Advisory Board meetings, as

well as thoughts and impressions that developed throughout data analysis.

Obtaining a general sense of the data. Notes and memos following each focus

group session were re-read and reviewed to develop a general interpretation of the data.

The initial 25% of transcripts were read and analyzed using microanalysis (Strauss &

Corbin, 1996) to develop initial, more specific categories emerging in the data.

Microanalysis is a form of open coding that involves reading "line by line" and analyzing

each phrase and key words that carry meaning for participants (Strauss & Corbin, 1996).

Concepts identified in this manner are rooted in the context in which they are found. After

microanalysis, the other 75% of transcripts were read, using the initial codes and themes as

a guide for further analysis of the transcripts (see Coding section). Appendix F includes the

transcript from Focus Group #1 as an example of coding.

Coding. Initial concepts were aggregated into a codebook which guided continued

analysis (see Appendix A). As each transcript was analyzed, emerging concepts guided

questions asked in later interviews and focus groups, and related concepts were synthesized for cohesion and clarity to describe a higher-order understanding of a phenomenon. Groups of related concepts are known as categories. Names of categories were developed based on emerging wording from transcripts, as well as related concepts found in the literature. Categories were explored in terms of their properties (specific characteristics that define a category) and dimensions (the range in which the category may be expressed or experienced; Strauss & Corbin, 1996). Categories were then related to one another to form hypotheses about the relationships between them and thus, grounded theory.

I kept memos after each reading, noting concepts that are emerging and how those concepts may be relating to one another and to my experiences. Memos guide future questioning that may be used and help the researcher to identify personal biases as well as the biases of participants. Recognizing these biases allows a researcher to understand how they may be influencing interpretation (Strauss & Corbin, 1996). These memos were used as an additional piece of data to formulate grounded theory.

Describing. A constantly comparing procedure was used to describe and connect themes. Themes were mapped visually using the Atlas software and a visual representation of the theory (the model) was developed.

Develop theoretical model. A grounded theory model was developed that guided protocol design. "Grounded theory" is defined as "…theory that was derived from data, systematically gathered and analyzed through the research process" (Strauss & Corbin, 1996, p.12). A grounded theory should explain some phenomenon occurring in the social,

educational, or psychological world. A visual model was developed as a reference for focus group members to review and critique.

Interpretation. Upon developing the grounded theory, it was checked with focus group members. These members confirmed or challenged various aspects of the findings described by the researcher. If there was disconfirmation of some aspect of the theory during a focus group or Advisory Board meeting, I made sure to clarify concepts and categories at later meetings.

Trustworthiness

While the nature of trustworthiness in qualitative research differs from parallel conceptualizations of validity in quantitative studies, it is important to establish the methods that will be used to ensure the accuracy of findings (Creswell, 2007). Lincoln and Guba (1985) established four aspects of trustworthiness that can be evaluated in reviewing qualitative research: (a) credibility, (b) confirmability, (c) dependability, and (d) transferability.

Credibility. Credibility can be conceptualized as being most similar to internal validity in quantitative approaches (Anfara, Brown & Mangione, 2002). Credibility in this study was established using triangulation and member checks.

Triangulation involves examining different sources of information and using that information to create a coherent explanation of themes (Creswell, 2007). I triangulated notes from focus groups and focus group transcripts to guide my interpretation. Member checking involves taking preliminary descriptions and analyses to key stakeholders for their review and feedback on accuracy (Creswell, 2007). I conducted multiple member

checks with focus group members to ensure accuracy of themes.

Confirmability. Confirmability involves the justification of interpretations and understanding of how the findings are rooted in the data (Anfara, Brown & Mangione, 2002). This can be achieved through the use of a peer debriefer (Creswell, 2007). A second reader, an Educational Specialist student in school psychology, read behind me and coded the same 25% of transcripts from focus group sessions that I initially microanalyzed. The debriefer and I discussed codes for verification, clarity, and accuracy (Miller, 1997).

Dependability. Dependability can be conceptualized as consistency in findings, and was developed by working closely with stakeholder participants, as well as my advisor as I conducted this research (Anfara, et al., 2002). Constant comparison was used to understand any negative or discrepant information (Creswell, 2007).

Transferability. Transferability deals with the ability of findings to be generalized beyond the context of a study and its participants. Due to the specific nature of a decision aid, this study sacrifices some transferability. However, purposive sampling ensured optimal representation of the variety of perspectives that exist within the specific group of participants. Using thick description also facilitated transferability by providing a rich understanding of the context of participants, allowing for shared experiences (Creswell, 2007).

Validity

Maxwell (2005) refers to validity as "the correctness or credibility of a description, conclusion, explanation, interpretation or other sort of account" (p. 106). He identifies two significant threats to validity: bias and reactivity.

Bias. I addressed the potential for bias by recognizing and identifying my personal biases and making them apparent to participants.

1. By designing this study, I make clear my beliefs that increasing parental capacity for joint decision-making with their child's IEP team will improve the relationship between parents and schools.

2. I also disclose that it is my opinion that the current ways in which parents and schools interact, are in many ways, unsatisfactory and in need of improvement.

3. It is also my perspective that there is a specific need for work with diverse parents in order to have their perspective heard and represented more fully in research and having their unique needs addressed in practice. I was an employee of the school district in which this study was conducted.

I disclosed my employment status to participants in the study. By utilizing a peer debriefer and conducting member checks, it is my aim to present my findings through a lens that recognizes my personal biases, but does not cloud the reality of the experiences of the participants (Maxwell, 2005).

The debriefer protects against bias by being a neutral, outside party who does not necessarily subscribe to the same beliefs and opinions, and reads the transcripts with her own interpretation. Use of the microanalysis process encourages a deep level of specific analysis that reduces possible bias. As we came to consensus on the emerging codes and themes, this established the confirmability of my findings.

Conducting member checks involved reviewing the themes, codes, and concepts that emerged from my reading and the reading of the debriefer with the original participants. This process allowed participants the opportunity to clarify or question the findings that resulted and to ask for further justification, requiring evidence from the transcripts that led to the connections that were made.

Reactivity. Reactivity was a significant validity threat for this study, considering that my main context of study was within the focus group interview setting, rather than a more naturalistic context. Utilizing a less naturalistic setting increases the potential for influence by the researcher (Maxwell, 2005). Again, while I cannot eliminate the effects of my involvement in the study on participants' responses, I can understand that my interpretation of findings will come through my personal lens, such as my training as a school psychologist, my perspective as a person without children, and my difference in SES and racial/ethnic status. Continued feedback from participants in the form of member checks (Creswell, 2007) is one method that assisted in the minimizing of reactivity effects.

Chapter 4

Results

Grounded Theory Model

One product of this work was to create a model of decision-making for diverse

parents of elementary-aged children with autism. To best illustrate the grounded theory

framework of these findings, a visual model of parent decision-making is provided. See

Figure 1. Based on findings from parents and professionals, a "traveling" or "journey"

analogy was utilized throughout description of the model and decision aid tool. This

reflects a recurring theme from parents and professionals that making decisions for a

child's special education services is an ongoing process incorporating many factors. As

one professional stated, "It's more of a journey, what I take with me, what I gather along

the way, the direction I go, and then, once I have all those experiences and knowledge,

what am I going to take from it" (Professional Co; 3:489).

The model encompasses the first two research questions addressed in this study,

while the discussion of the decision aid tool, which is based in the grounded theory, will

address the final research question.

Research Questions

For each research question, relevant components of the model are discussed,

following with the illustration included in Figure 1. Additional illustrations are included in

Figures 2-35, to describe relationships among codes and categories within the larger

model.

Figure 1.

Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged

Children with Autism in Kansas City, KS Public Schools.
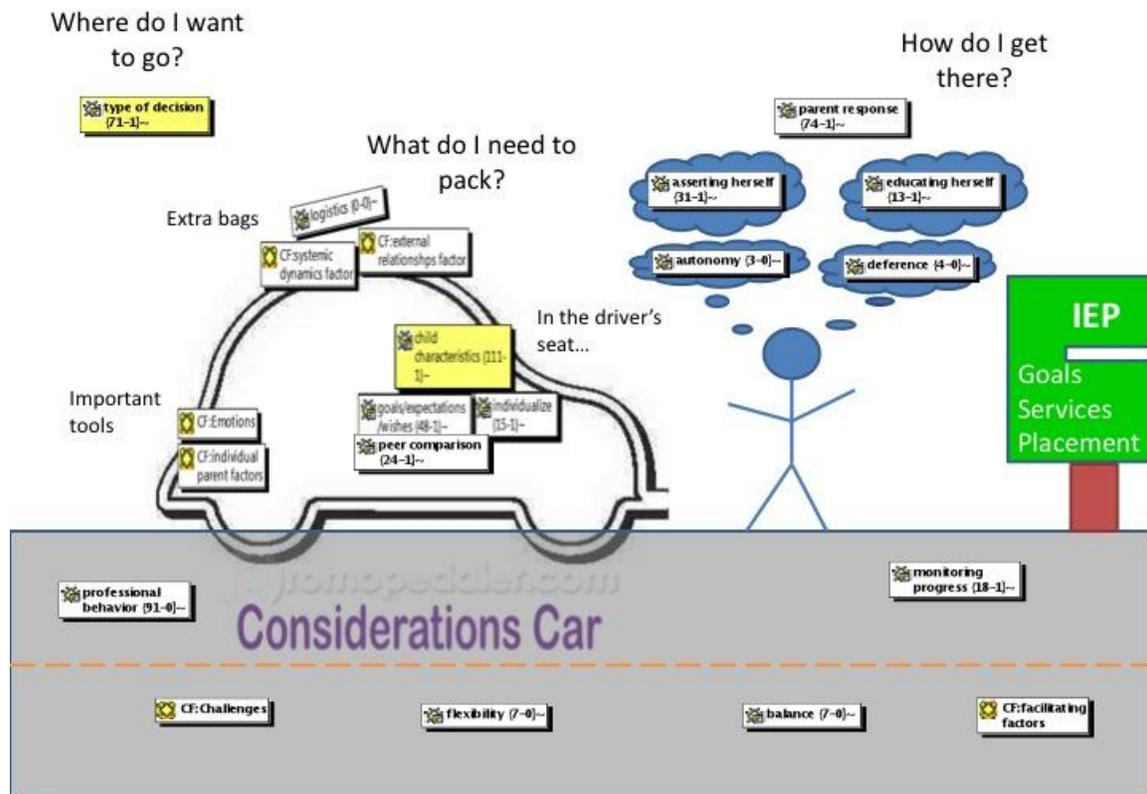
Research Question 1: What factors (e.g. environmental, behavioral,

relational) influence the decisions made by diverse parents of elementary aged

children with autism? Factors identified by participants focused outside of and leading up

to an IEP meeting. Participants discussed the variety of issues parents found themselves

facing (coded as *type of decision*), which tied closely to individual characteristics and

needs of the child, goals for the child's future, and expectations for peers. Parents also were

influenced by personal characteristics about themselves, including experiences, personal knowledge, and emotions. Additional influences included factors of the systems parents found themselves operating within, such as the family, school system, and other logistical factors such as transportation or work schedules. The decision-making process emerged as three questions parents considered for themselves: (a) Where do I want to go? (b) What do I need to pack? (c) How do I get there?

Where do I want to go? When planning a trip, the first question a traveler asks is "Where to?" Thus, the initial component of this model deals with understanding the type of decision to be made to determine where this journey is going. When initially asked about the types of decisions parents have to make in IEP meetings, one parent responded, "I don't really feel like I ever have anything to say about the educational decisions." (Parent Te; 1:50) Initial perspective from some of the mothers indicated that they felt their primary role when they attended meetings was to take in what the school was doing, and to speak up if they disagreed with anything they found within the IEP. As parents discussed the question further, several issues emerged. These issues were coded as *type of decision* and included questions and concerns about such issues as (a) social skills, (b) behavior, (c) communication, (d) transition to middle school, (e) eligibility for other available programs or services within the district at other schools, (f) understanding data and progress on goals, (g) medication, (h) work demands, (i) puberty, (j) self-help skills, (k) service time, (l) diet, (m) vaccinations, (n) finances, (o) finding support from other parents or experts, (p) the future, and (q) alternative treatments. Professionals reiterated many concerns heard from parents, but also added the following: (a) placement, (b) behavior intervention plans, (c)

IEP goals, (d) assessments administered at district and state levels, and (e) modifications and accommodations. *Type of decision* also related to *child characteristics, goals/expectations/wishes, individualize,* and *peer comparison.* Each of these codes influenced the types of decisions parents were considering and would be influenced by the decision as identified by the parent.

What do I need to pack? Travelers preparing for a journey bring different tools and bags with them along the way. This question encompasses factors important for parents to consider as they work with their IEP team. Thus comes the name for the *Considerations Car* in Figure 2. The *Considerations Car* is divided into three components a) In the Driver's Seat, b) Important Tools, and c) Extra Bags. Within each of these components are categories (also known as code families) and codes representing different aspects that parents reported taking into account when making decisions about their child with autism and his/her special education services.

In the Driver's Seat. In the driver's seat of the Considerations Car are codes that emerged based on parent's feelings that the child is the focus of the decision-making process. Priorities that "drive" the Considerations Car include *child characteristics*, *goals/expectations/wishes* for the child, and the importance of being *individualized* to the child's characteristics, keeping in mind the *peer comparison,* or understanding what is typical for children the same age.

Figure 2.

Grounded Theory Model of Factors "In the driver's seat" for IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools.
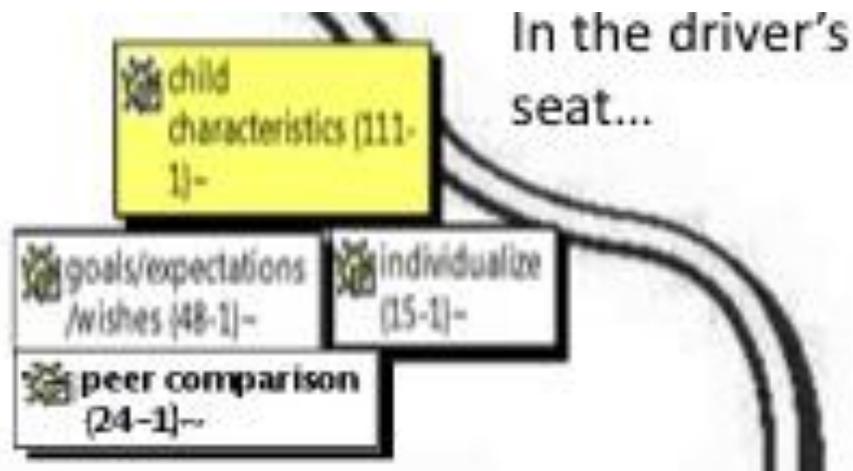
Child characteristics refer to specific, unique features of a child that may factor into a decision. This includes (a) speech, (b) behavior, (c) cognitive capacity, (d) social skills, (e) preferences, (f) interests, or (g) responses to different people, interventions, or medications. One parent shared her son's unique interest: "[My son] was a ceiling fan baby. He was knocking on the door, like, 'Trick or treat, smell my feet, let me see your ceiling fan.'" (Parent N; 1:315) Parents indicated that along with understanding these characteristics and how each child is different, there is an acceptance of the child as they are. As one parent said, "…with autism, that's the challenge, the kids are so different. I mean, you can't have two kids that are the same." (Parent Ta; 1:261) Parents reported *uncertainty* about what the future would hold for their child:

> And my son is 7, so…I wonder what he's going to be like when he's 10, like I
> wonder if I'm going to have to still be helping him get dressed. Because he can't do

that now…I have to literally walk him through each step, or do it for him. (Parent

Te; 1:255)

Parents described how their child's characteristics related closely to the types of

goals, expectations, and wishes they had for their child. A range of expectations were

shared:

And what we wish is…at least, he will be able to change his diapers, dress himself,

eating properly, going to the restroom, and sit nicely, don't go and run. (Parent K;

1:357)

I really do expect [him] to be the CEO of some Fortune 500 company. I mean, you

all laugh, but I am serious, I tell him that every day. (Parent N; 1:361)

Sometimes, these differences in expectations or goals existed among members of the IEP

team. Participants reported that the focus of goals or expectations could seem too

"academic focused" to some IEP team members, and not focusing enough on changing

behavior or encouraging communication skills. While for other team members, goals and

expectations were not focused enough on helping the child to fit in with typical age

expectations, including academic skills.

Considering these unique *child characteristics,* and how those characteristics drive

goals, expectations, and wishes for the child, it was vitally important for parents to feel that

their child's IEP was *individualized* to reflect these unique characteristics and to help their

child reach the expectations, goals, and wishes parents had for them, although frequently

there was a feeling that IEPs and services were not individualized enough.

What I would like to see is, my IEP goal, my IEP team take [my individual child's

needs] into consideration, and let's really break down that goal or that behavior, and let's not make it what every child in there is doing. I really want it catered to [my child's] needs. (Parent N; 1: 90)

Parents mentioned that they felt that their child's goals were pre-set, and weren't individualized enough. Parents felt that sometimes it was almost a cut and paste for their child's goals from another student's IEP, or that they weren't consulted about the goal before it was written.

While being *individualized* and considering *child characteristics* was driving decision-making for parents, they also were concerned with *peer comparison*, or understanding what is typical for a child the same age to be doing. Frequently, parents used that *peer comparison* when setting *goals, expectations, and wishes* for their child.

…you're not really sure, you know, where they are in comparison to other kids because…I guess my philosophy with autism is, you're trying to work to get them as close to normal as possible, but you know that there's some limitations, and so my goal was always, I want to get her as close to what the other 5th graders are doing as possible, that means if, if we can only pull her out of the classroom for 30 minutes as opposed to 60 minutes… (Parent Ta; 1:106)

Important tools. Other themes emerged as influential to parent decision-making, related to parents' personal characteristics and emotions. While the child's characteristics in comparison to peers drove the need for individualized goals and expectations, parents also reported a variety of personal characteristics that influenced how they approached making decisions. These overarching categories were *Emotions* and *Individual Parent*

Factors. Emotions included a range of challenging feelings that parents faced as they approached decisions for their child. The main emotions emerging from parents' stories were *uncertainty, confusion, overwhelming*, and *frustration*. See Figure 3 for a visual representation of this code family. Note that arrows included in each graphic are bidirectional, indicating a mutually influential relationship. *Individual Parent Factors* are characteristics about parents that participants reported having an impact on parent decision-making. These factors impacted parent IEP decision-making to differing degrees based upon *individual experiences*, *parent characteristics, parent knowledge*, and *faith*.

Figure 3.

One of the "Important Tools" in IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Emotions Factor.

"And they don't go through it in detail, per page, per page, I mean, it's just kinda like, here it is and this is you know, what we're doing."

"I don't even know what to expect moving into next year." 1:245

uncertainty {25-1}~

overwhelming {19-0}~

CF:emotional factor

confusion {24-0}~

Frustration {13-0}~

"I find myself a lot of times in a meeting, you know when they're saying, A will complete so many tasks with so much percent accuracy, it's like, I can't, I'm just like, did she meet the goal? Are we seeing progress?" 1:106

"Because you know B will get these IEPs and these skills, and master them, and then he'll sit for a whole semester doing nothing and that's unacceptable." 1:656

Emotions described by participants included *uncertainty*, or being unsure about what the right next step is to take, as parents weighed different *types of decisions* available to the child. One parent shared a decision she was trying to make about changing schools:

> And I just keep thinking to myself, what if I change him to another school? You know, to see if he might do better. And I just keep thinking, should I change him should I change him? And I just don't know what to do, because they say that transitioning could be a big issue on the kids, you know, when they move.
>
> (Parent L; 1:174)

See Figure 4 for a visual representation of the association of uncertainty to other codes. Bidirectional arrows indicate a mutually influential relationship among codes.

Figure 4.

Links Within IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in the Kansas City, KS Public Schools: Emotional Code Uncertainty and Associations with Codes Child Characteristics, Type of Decision, and Monitoring Progress.
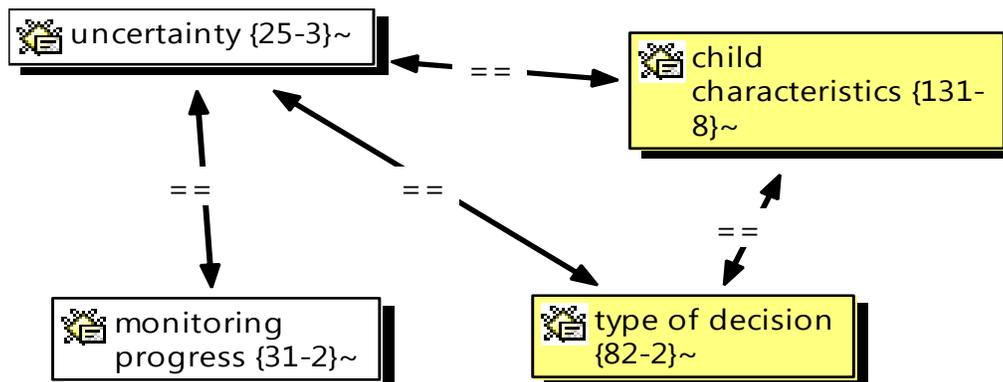
Parents also reported *uncertainty* about dealing with the school – wondering about quality of instruction or intervention. When this type of uncertainty arose, parents and

professionals discussed the importance of *monitoring progress* in a child's behavior or other skills and being able to adjust quickly to changing skills or needs of the child. One mother described her experience of uncertainty moving into the district and being informed about the special program that her son would be eligible for:

> 'Right, well let's just put him over here [in a special program].' Ok, but he's going to be over there, but what does that really mean, what class is he really getting? What are they going to be working on? And he has a para from [other school district], is he going to get a para? And they're like, no, he's not going to get his own para. And I was like, 'oh, really.' (Parent N; 1:243)

Parent N reported monitoring his progress in this classroom and the importance of following up with her son's IEP team to determine the best placement, including what teacher would be working with her son the following year. Other parents were also uncertain for what the future might hold, or about how they had handled situations or issues in the past.

> …and even like now, I'm always asking, what's going to happen when she gets to middle school? (Parent Ta; 1:245)

> I always still feel like you know, she maybe could have been better if I would have known more, you know. Now, could she be? I don't know, but you always just wonder. (Parent Ta; 1:458)

> Another *Emotion* that participants described was *confusion*, stemming from

difficulty understanding information related to or within the IEP. This information included terminology used by professionals, or roles of various members of an IEP team.

One parent, Te, shared her experience:

> I can tell you that the IEP thing is kind of confusing. I have a really hard time
> understanding. So a lot of the times I don't even know what really is going on
> actually. 'Cause, they have all these different goals and what they're gonna meet,
> but at the same time I'm like, 'I don't wanna go through this whole thing and read
> this!' And they don't go through it in detail, per page, per page. I mean, it's just
> kind of like, here it is, and this is you know what we're doing. I mean, you're in an
> IEP meeting for maybe 15, 20 minutes.   (Parent Te; 1:098)

Figure 5.

Links Within IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in the Kansas City, KS Public Schools: Confusion and Associated Codes Lack of Control and Lack of Knowledge.
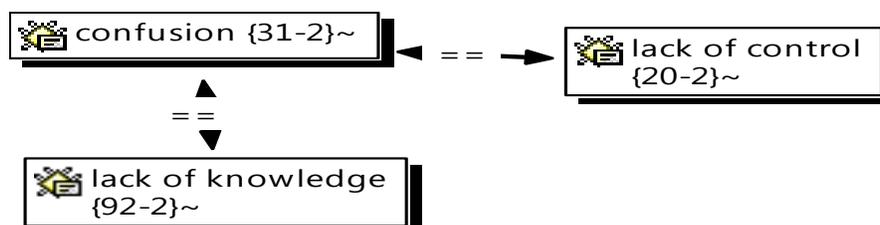
This *confusion* seemed to relate to a *lack of knowledge* as well as a *lack of control.* Parent Ta shared confusion associated with a lack of knowledge around services that were available to children in the district: "One thing, I don't really know what kind of services my daughter is eligible for, or has the right to receive" (Parent Ta; 1:604). *Lack of control* was also associated with *confusion* for parents. Parents reported being confused and needing a guide to know what is going on at school for their child.

> That's another thing, when you're going in….I guess, they never broke down the

whole organization to me. When I came to [school district], you know, he was just

thrown into the STEPS [special program] class. Nor did [my son] know what to

expect. I was looking for someone, like a tour guide, like I'm looking, I need to

know what's going on. (Parent N; 1:239)

Parents also faced *overwhelming* emotions from such things as an overabundance

of information, by the number of people present in an IEP meeting, or with different

questions and concerns they might have about their child.

One thing that really turned me off when we went to her IEP meeting last year, and

it was like a whole big fiasco. There were like 15 people at this meeting, and I was

like, 'I've never even seen all you all.' And it was like, I didn't even, I don't know

what she's getting. (Parent Ta; 1:612)

Figure 6.

Links Within IEP Decision-Making for Diverse Parents of Elementary-Aged Children with

Autism in the Kansas City, KS Public Schools: Code Overwhelming and Related Code:

Lack of Support
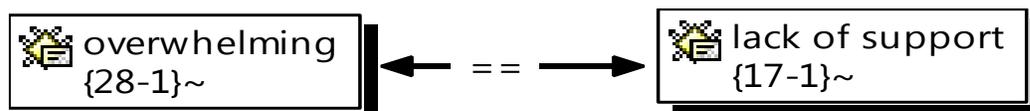
This feeling of being overwhelmed appeared to be related to the lack of support a parent

had. One parent stated she felt that she was "given the diagnosis [of autism] and thrown out

to the wolves" (Parent Te; 1:273). Another parent reported feeling like she was "grasping

at straws" (Parent Ta; 1:443) when she noticed her daughter not progressing as she should,

until she was able to get a referral to a professional who helped her understand her child's

autism.

Individual Parent Factors are characteristics that parents and professionals

identified about parents that influenced their decision-making. These included

characteristics of parents, as well as experiences parents had and knowledge they held. For

some parents, faith also factored into parent considerations about what was best for their

child. These factors also meant that parents had their own ideas about what was best for

their child. See Figure 7 for a visual representation of the Individual Parent Factors code

family.

Figure 7.

One of the "Important Tools" in IEP Decision-Making for Diverse Parents of

Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Individual

Parent Factors.
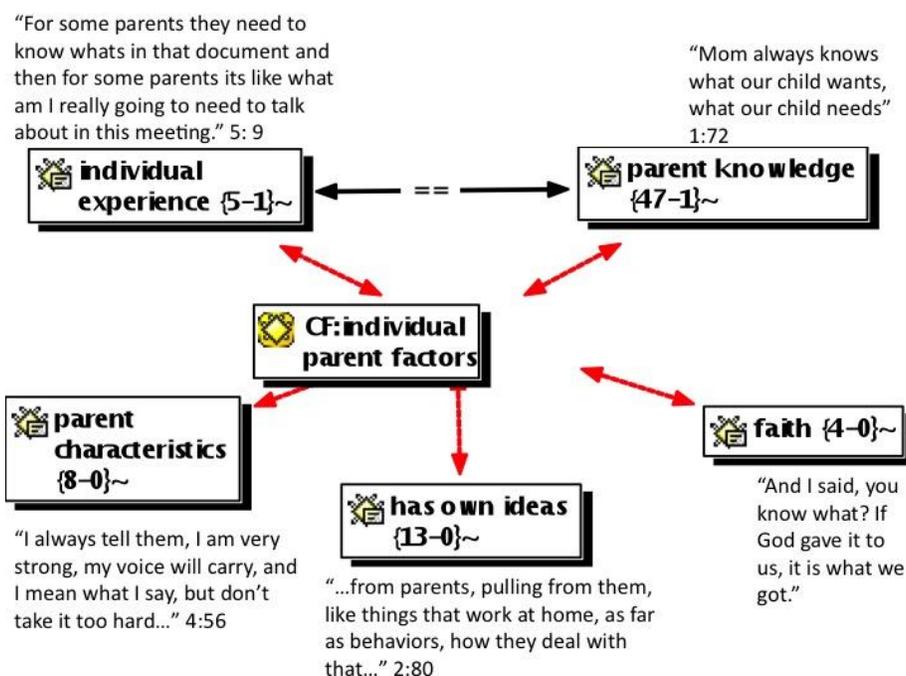
Professionals and parents identified an array of parent characteristics that included

parent education level or profession, comfort level in an IEP meeting, work or personal schedules, culture, or assertiveness. According to participants, these characteristics all may affect how a parent may interact with their child's team to engage in decision-making. One parent shared her personal characteristic of being an assertive participant in her IEP meetings:

> I always tell them, I am very strong, my voice will carry, and I mean what I say, but don't take it too hard. I'm just here to do the best for [my son], and…if I disagree with you it doesn't mean that I dislike you, I just mean that I want what's best. (Parent N; 1: 056)

For some parents, having *faith* or a belief system lead to an interpretation of their child's disability and how they dealt with it. Parent N felt like there wasn't time to consider faith: "Autism is such a shocker you don't have time to think about that kind of stuff," (1:343). One parent, K, shared her belief that "…if God gave it to us, it is what we've got. And I love him, and he's a gift" (1:357). Another parent, Ta, shared that while she didn't feel she was really religious, and didn't feel that her faith had made her decide whether or not to do something for her daughter, she still felt that

> I trust in God, and I believe that he made her the way that she is for a reason. And that's something that I had to deal with in the beginning. It was hard for me to accept that diagnosis. (1:347)

Parents in this study reported *individual experiences* that were unique and distinct from other parents in working with her child's IEP team. This reflects how each child's autism and the family's experience with it were very unique. Parents shared about their

experiences working with the greater system (e.g. getting on the autism waiver available in the state of Kansas), and with outside support agencies (e.g. Families Together, the Parent Training and Information Center for the state of Kansas). For some parents, their experiences changed over time. One parent, Te, who shared that she felt confused by the mass of information, later in the study shared that

> Now, what I did last IEP, is I asked for the IEP before the IEP meeting. Because I wanted to literally read each page. I wrote down questions, I highlighted things. So when I went to the IEP meeting, I was able to tell them, 'This is what I have questions about.' (Parent Te; 6:045)

Participants reported that parents' individual experiences helped them to develop *parent knowledge,* parents' expertise and intuition about their child. *Parent knowledge* is different from the knowledge that professionals have. Parents understand their child's unique characteristics. "Mom always knows what our child wants, what our child needs" (Parent L; 1:116). To develop this knowledge, mothers report activating their *support system*: "I talk to a lot of other mothers. I have talked to a TON of other mothers. And they have been the most helpful to me, with decision-making. For a lot of my educational needs" (Parent N; 1:193). Parents activate their accumulated *parent knowledge* when they decide upon their *parent response.* Their response could involve *educating herself* about options or *asserting herself* and making her ideas known to her team or service provider. By *asserting herself*, a parent has decided to share *her own ideas.* The code *has own ideas* refers to the ideas that a parent has based upon her parent knowledge. She may or may not choose to share those ideas during an IEP meeting or in communication with her child's

team.

> And the speech thing, like I said, I asked them to increase his speech, and they were
>
> like, 'No, it's okay, 20 minutes, three days a week, it is okay.' No, it is not okay. My
>
> son is not verbal at all. He don't say anything. He don't say Mom, Dad, anything. I
>
> think they could hear us a little more too. (Parent K; 1:550)

Because some parents reported that they would use these ideas and *assert herself* to let her

ideas be known, these codes are also linked. See Figure 8 below for a visual representation

of these links.

Figure 8.

Links Within IEP Decision-Making for Diverse Parents of Elementary-Aged Children with

Autism in the Kansas City, KS Public Schools: Parent Knowledge Associated with

Individual Experiences, Child Characteristics, Parent Response, Educating Herself,

Asserting Herself, Has Own Ideas, and Support System.
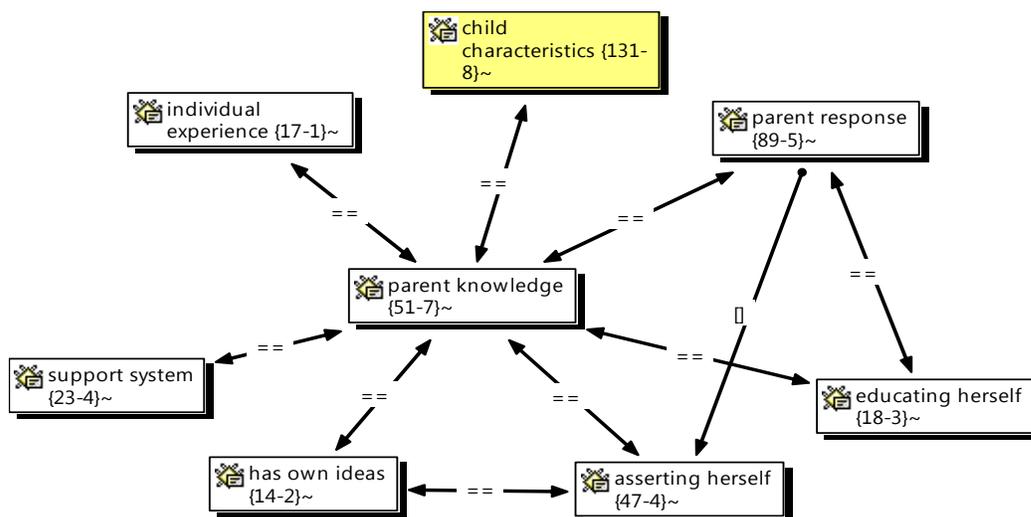
Extra bags. While the child drives the decision and parents report carrying

important, personal tools with them as they embark on this decision-making journey, there

are also extra bags that may be carried along the way and influence how decisions are made. These extra bags include the impact of relationships among family, friends, or with other professionals. Extra bags also included the systems that parents and their children are a part of such as the school system, classroom or family. Professionals also reported logistical factors that were considered. Examples of logistical factors are the distance a parent lives from the school, available transportation, or activities and needs of other siblings.

Figure 9.

One of the "Extra Bags" in IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Systemic Dynamics Factors of Consider Context, Family Considerations, and System Characteristics.

"My son Is used to being in a class with 4 children, and that was my concern is that I didn't want him to be thrown into a class where there was like 15 children..." (1:209)

consider context
{31-2}~

==   ==

CF:systemic dynamics factor

system characteristics
{73-2}~

==

family considerations
{22-2}~

"But don't you think that the doctors and the school and the early childhood center, they need to have a connection somewhere." (1:441)

"And my husband, he had his brother...and he did have mental retardation. And my husband say 'I am not prepared to have another kid in my life, to take care of like that." (1:357)

See Figure 9 for a visual representation of the relationships among the code family *Systemic Dynamics.* Note that all arrows are bidirectional, indicating associations among

variables. *Family considerations* are aspects of family life that are influenced by or have influence on the child and the decisions parents are making. One parent described having another family member with a disability, and how that influenced her husband's perspective on having a child with autism:

> I think my husband accepts a lot more. Because at the beginning it was really hard for him, because of his brother [who had an intellectual disability]. But, we've been seeing [our son] do a lot better, because his brother was a 6 month baby brain. Four months ago, he died with a 6 month baby brain, and he was 49 years old. And [my son] is 18 months, and it is a lot better than him. (Parent K; 1:357)

> Another influence on decision-making is the context in which the decision is being made. Thus, *consider context* was another code that emerged as parents and professionals discussed aspects of the environment in which a behavior or skill was expected to be learned or demonstrated. This could mean considering the differences between home and school environments, or between different schools or classrooms, and why a child may have different needs or behaviors in those different places. For example, one parent shared about her experiences in the differences for home versus school in using the Picture Exchange Communication System (PECS), or as she referred to it, "the book," and compared that with her experience with using an augmentative communication device (this parent called it the "electronic box").

> The school…had a good experience with [my son] with the book. But the mama, it's too much, it's too complicated for me. And I told him, you know, we're going to stick with the electronic box. And, it worked. It was the best thing. And now, you

just have to talk to him. He'll say anything, whatever comes to his mind. He'll say

it. (Parent N; 1:387)

Three of the parent participants had moved into the district, and all of them mentioned

seeking information about the type of classroom or program that would be available or best

for her child prior to enrolling the child in a particular school. Another parent who had been

with the school district for the entirety of her son's schooling discussed the possibility of

evaluating different classrooms within the same program to determine if one might be a

better fit to encourage his speech. Another parent reported noticing a difference in her

son's skill growth when he was in an inclusive classroom versus when he was in a

classroom with only children with disabilities. Linked to *consider context* were *child*

characteristics that interact with various types of contexts, as well as association with

system characteristics and *family considerations*. See Figure 10 for a visual representation

of this linkage, noting that the bidirectional arrows indicate association, not a causational

relationship.

Figure 10.

Links Within IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in the Kansas City, KS Public Schools: Consider Context Associated with Child Characteristics, System Characteristics, and Family Considerations.
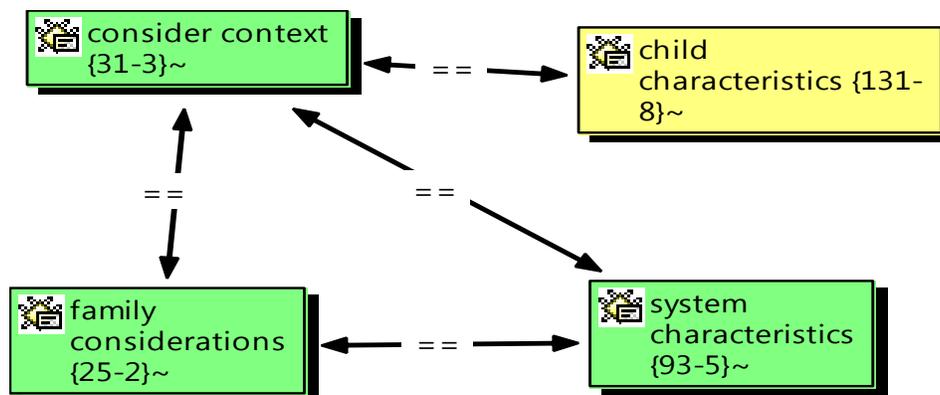
System characteristics identified in this study included aspects of the school district, the law or the community that influence how decisions were made by parents. See Figure 11 for a visual representation of the system characteristics code and codes that are associated with it. Parents reported wanting a better understanding of the system and all of its parts:

…they never broke down the whole organization to me (Parent N; 1:239)

…what kinds of programs do they have for autistic kids once they get to middle

school? (Parent Ta; 1:245)

Parents also described working with the law, and how it impacted financial decisions for the future. As Parent K shared:

We have now a savings account for him, and we heard that we can't have that after

he is 18. We can't have a savings account for him after he is 18, because if he has

money, he will not get support from the government. It is something that maybe we

need to know better. (1:756)

Parents also reported challenges with the system, when it appeared that the district had a *lack of resources* or *lack of personnel.* Parent N and Parent Ta compared their experiences with resources and personnel in the current school district to the district in which they lived before:

Before I moved here, there they had a library, if there was a book you needed, if there was any type of video training, I know they had videos about like ABA types of training. You could check out those videos and keep it out for two weeks. (Parent N; 4:22)

I feel like there was just a lot more support in her other school. And maybe they just don't have the resources, or the money. 'Cause like, we were in [other school district], and we moved to [another school district], and the principal was like, we're going to hire another teacher to work specifically with her. And I thought that was great. (Parent Ta; 1:245)

Another factor that linked to *system characteristics* was the influence of the behavior of professionals within a system. Parent Ta discussed professional behavior and how it influenced her decision to enroll her daughter in a particular school in the district:

…they have teachers there that, if she starts to go into one of her moments, you know, somebody can say well I know what's wrong with her, they're not going to be yelling or putting her in time out or something because somebody there is going to have experience with autistic kids you know, to say okay, she's exhibiting a behavior…so that was a big factor in choosing [her school] was their expertise… (Parent Ta; 1:219)

Figure 11.

Links Within IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in the Kansas City, KS Public Schools: System Characteristics Code Associated with Professional Behavior, Lack of Personnel, Lack of Resources, Family Considerations, and Consider Context.
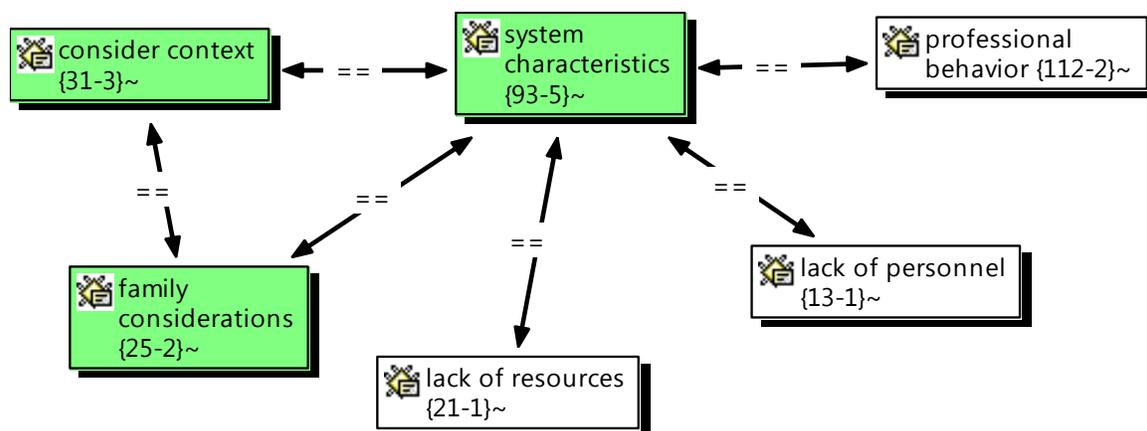
Professionals also mentioned the influence of *logistics* on parents' ability to participate in decision-making with their team. This included distance from home to school, parents' work schedules, transportation, communication tools (whether or not a phone was in working order), and parent language.

External relationships were described as other relationships, outside of the one

between the parent and the child, that influence decision-making for parents. When

factoring in external relationships, parents consider (a) the *perspectives of others*, (b) their

relationships, and (c) may activate their *support system*. See Figure 12 for a visual

representation of this code family. Arrows represent bidirectional associations.

Figure 12.

Some of the "Extra Bags" in IEP Decision-Making for Diverse Parents of

Elementary-Aged Children with Autism in the Kansas City, KS Public Schools: External

Relationships Code Family.
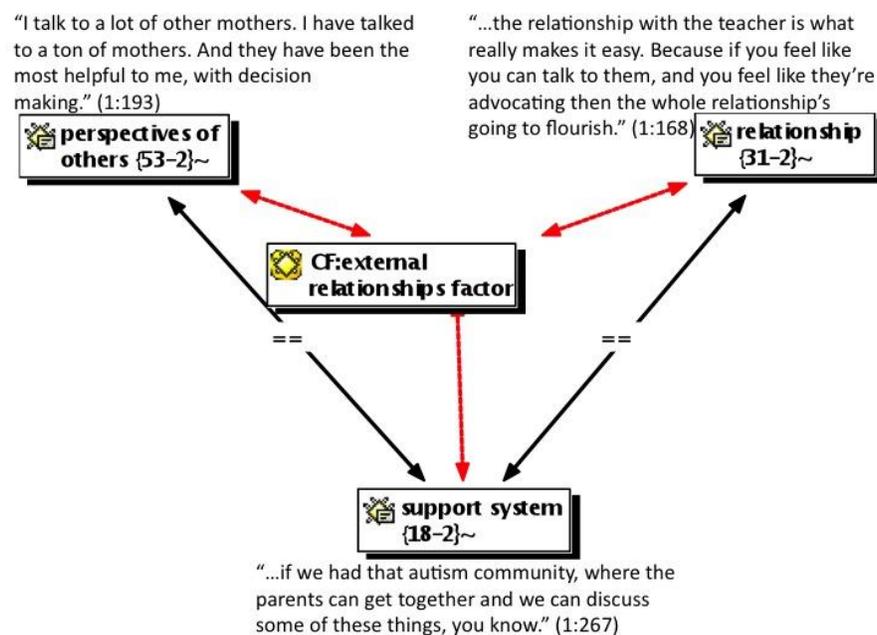
Perspectives of others refer to receiving input and opinion from other people

besides school professionals. This includes other family members, such as a spouse,

sibling, or in-law; other parents, consultants, or even strangers out in public. Participants

described that sometimes these perspectives were solicited while other times they were not.

When parents consider the perspectives of others, they may be doing that through activating their *support system.* Parents described how these perspectives influenced their own feelings or perspectives about their child.

> Family, like especially my mother-in-law would come in and be like, 'A can talk, y'all are just not doing such-and-such.' And it was like, no, she has these issues you know. And I always used to think it's because they can't accept that she has autism, and so, they want to make her normal when she's not. But then when I stood back and looked it was like, well, she's doing it. (Parent Ta; 1:407)

Figure 13.

Links Within IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in the Kansas City, KS Public Schools: Perspectives of Others Code Associated with Support System and Identifying with Others Codes.
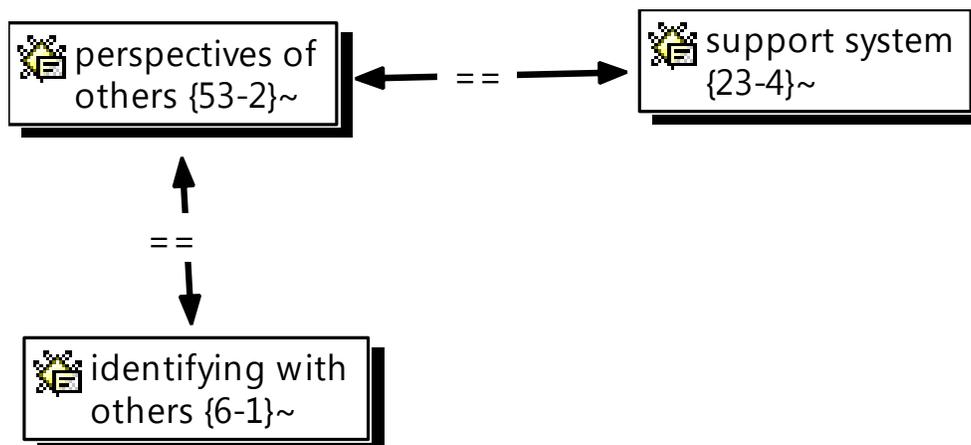
Within the focus groups, parents were *identifying with others* when sharing their stories. One mother talked about her feelings when another mother posed the question that changing a child's diet could cure autism or make symptoms go away.

I mean, I do know a ton of parents that have did the diet and it has made a major

difference for their child. But for me, and mine, the boy is still slapping himself

upside the head and he is still on the strictest of diets. He don't have corn, he don't

have wheat, he doesn't have milk, he's you know, soy free, chicken free, egg free,

now you tell me what in the world can I feed that child? But, is he communicating?

He says a whole lot of things, but he's not age appropriate. (Parent N; 1:425)

Relationship refers to the interactions among adults involved with a child.

Participants felt that a relationship was important to develop when working on making

decisions, and to linking relationships in order to build a *support system*.

You have to be on the same page. (Parent N; 1:322)

To be supportive of one another. You know, the biggest concern is for the child.

(Parent Te; 1:323)

Figure 14.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of

Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Relationship

Associated with Communication and Support System.
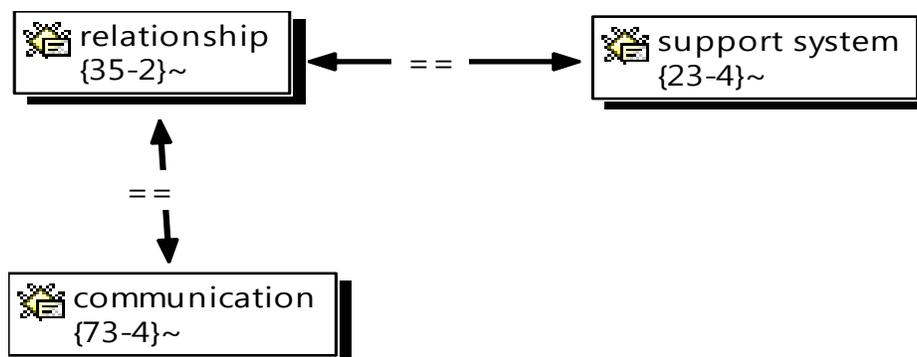
Participants discussed the importance of *communication* to that relationship. From

communication, conversations can happen, that then leads to a bond and understanding among people working with a child.

> I totally agree the relationship with the teacher is what really makes it easy. Because if you feel like you can talk to them, and you feel like they're advocating then the whole relationship's going to flourish. (Parent Ta; 1:168)

The *support system* described by participants was a system of people who had been helpful in the past or present. Most of the support systems that parents mentioned were teachers that were especially helpful, doctors or other professionals who supported them as advocates, and other family members who helped support parents. "My mom really was my biggest, strongest supporter in a lot of ways." (Parent N; 1:409) Parents discussed the need to organize their own form of a *support system* among parents in the district, to educate others and address common issues.

> And see if we had that community, an autism parent group, we could go out into the schools and do just a special session on that. And invite the other parents to come out with their students and open up the discussion. But, because we don't… (Parent N; 1:522)

Additional linkages to *support system* are discussed in the section of the Results describing *facilitating factors*.

How do I get there? The next question in the journey model of parent decision-making refers to the types of actions parents may choose for themselves as they prepare for an IEP meeting. In keeping with the travel analogy, considering "How do I get there?" is like choosing among the routes one may take to get a destination. A traveler

could choose to take one street or highway the entire way, or some combination of streets and roads. Different travelers may plan out different routes. This group of possible parent responses (or travel routes) was categorized as *parent response.*

Parent response encompasses four different ways that parents might have chosen to respond when faced with decisions. Frequently, but not always, these responses occurred when there was disagreement between the parent and members of their child's team. They might choose a single response or a combination of responses. The four main types of responses that were heard from participants were (a) *asserting herself,* (b) *educating herself,* (c) *autonomy,* and (d) *deference.* See Figure 15 below. Note that arrows are bidirectional, indicating associations not causation.

Figure 15.

"Where Do I Want to Go" From Grounded Theory Model of IEP Decision Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Family Parent Response.
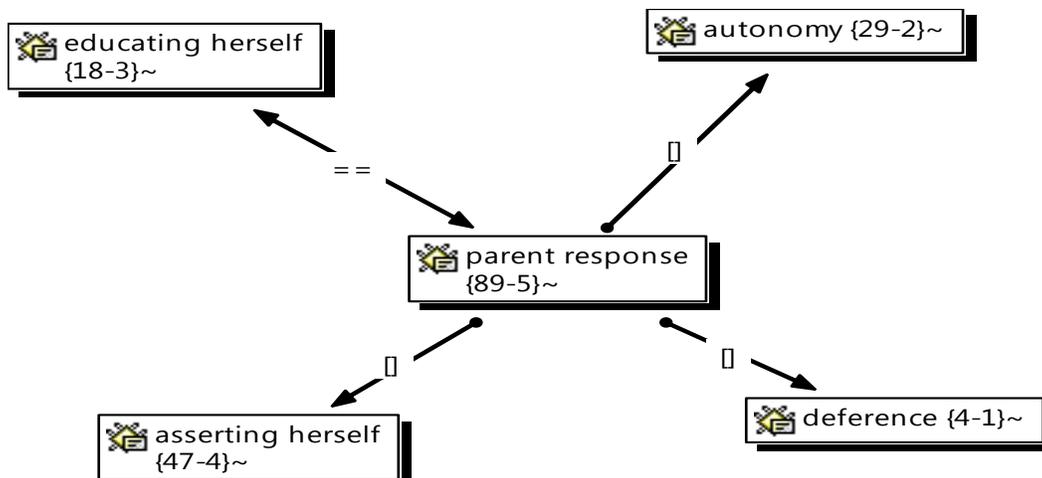
Parents reported *asserting herself* as an attempt to have her ideas heard by the

school personnel or other professionals. It might include disagreeing with suggestions, stating a strong opinion, or making her own ideas heard. *Asserting herself* links to *has own ideas* and *persistence.* Some examples of *asserting herself:*

> And by the time it was time for him to go to school, they wanted him to get the shot. I refused. They were like, the only way you can refuse it and for him to go to school is you have to have his doctor sign it…And I was like, okay. I went to the doctor, and she didn't agree about it. And I was like, well that's my beliefs, and I don't want him to have it. (Parent L; 1:472)

> So it's like, your son, what is the strategy of getting him to talk? Are we talking about a communicator box? Who are the people who can get it? All of those people that are on that – I have literally, 15 people that come to his IEP. But I make every last one of them tell me what has happened during the time that they have evaluated him. (Parent N; 1:390)

See Figure 16 below for a visual representation of the linkages to the code *asserting herself.* Note the bidirectional arrows indicating association not causation.

Figure 16.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Asserting Herself Code Associated with Persistence and Has Own Ideas Codes.
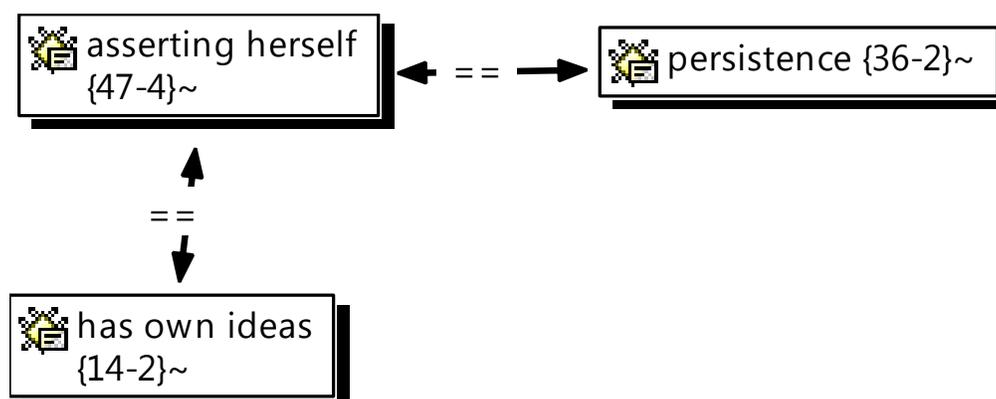
Another possible response described by participants was *educating herself,* a mother's taking of initiative to find out information to help her make a decision. This could include researching treatments, information about autism, school choices, the IEP process, the law, or other questions she may have. Parent N described her choice to educate herself, when she felt the doctor didn't set her expectations accurately for what to expect for her son with autism.

> He did not set my expectations. I was thinking, 'oh I'm going to call early childhood services, and I'm not going to have to deal with this no more.' I mean, it's a lifelong issue. It's -- you have to do your own education, you have to do your own research. (Parent N; 1:435)

See Figure 17 for an illustration of the linkage to the code *educating herself.*

Figure 17.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Educating Herself Associated with Lack of Knowledge Code.
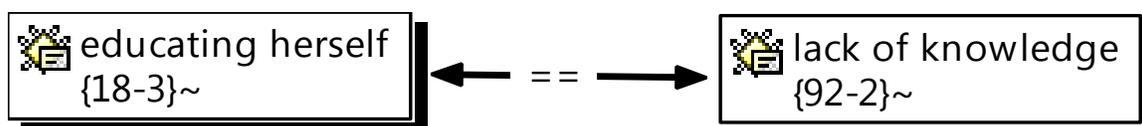
The code of *educating herself* links to *lack of knowledge,* as frequently parents reported that they were missing information and sought to educate themselves to know how best to move forward.

Another possible response that participants reported was that of *autonomy,* the desire to be independent and organizing or advocating on their own, without the school or other professionals overseeing what they were doing. This code emerged from parents' feelings that they wanted to come together as a group and organize to become an educational and supportive force for parents of kids with autism as well as to be advocates within the school district and the community.

> We don't have a strong Wyandotte County Autism Society. Yeah. And I think that's a major downfall. Because, I think the more we stick together the more services we can get for our children. (Parent N; 1:193)

Figure 18.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Autonomy Associated with Support System.

autonomy {29-2}~   ==   support system {23-4}~
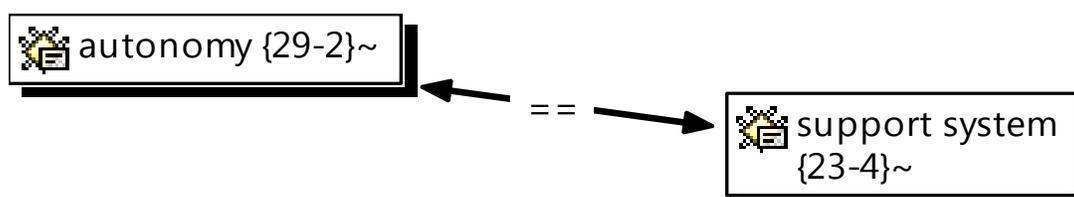
Linking to *autonomy* is the code *support system*. Parents could seek *autonomy* for themselves individually as well as a group, further broadening their *support system.*

Deference was another potential parent response, meaning deferring to professionals and their recommendations. While initially in the focus groups this response was introduced by professionals, parents recognized this possible response as well.

I think there's some parents that they'll say, 'What do you think? What do you think?' They are looking to us, maybe they come from a cultural background of trusting the school to make that decision. They're maybe not familiar with being part of that decision-making. (Professional Ca; 2:128)

I think a lot of times we as parents, we kind of let the school…we think, well they are educators, they know what they are doing. You know, I'm not the professional that they are, when it comes to curriculum and what programs they use to teach the children." (Parent Ta; 1:44)

The road sign in the model represents the parent moving forward and going into the IEP meeting to discuss goals, services and placement for her child. This also indicates how these factors are all influencing the parent prior to entering an IEP meeting.

*Along the road…*Parents and professionals identified several factors that influenced the ease of parents' journey through the IEP process. If some factors were present, then it usually meant that the experience went more smoothly. These factors were categorized as *facilitating factors.* If other factors were present, the experience tended to be more difficult. We called these *challenges.* Those will be discussed in the next section, as they tie more closely to the second research question. Some of the factors could be positive or negative, depending on their manifestation. These included factors such as (a) *professional behavior,* (b) *flexibility,* (c) *balance,* and (d) *monitoring progress.*

Figure 19.

"Along the Road" in Grounded Theory Model of IEP Decision-Making for Diverse

Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools:

Factors Affecting the Journey, Including Professional Behavior, Flexibility, Balance,

Monitoring Progress, Challenges, and Facilitating Factors.
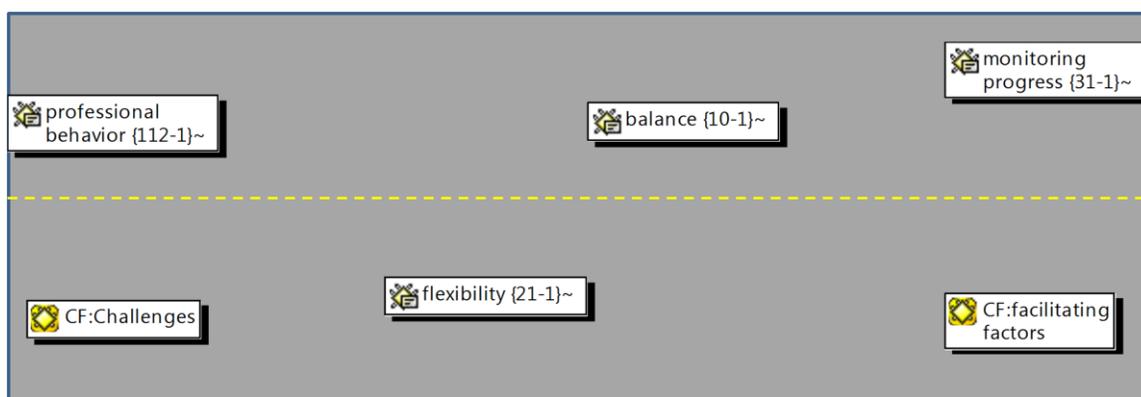
 Professional behavior was often a response from professionals to parent requests as they worked together for the child. Sometimes, parents reported that professionals were resistant to a request that they made, made parents uncomfortable in some way, or left a parent feeling dissatisfied.

> 'Cause you can get intimidated. 'Cause they're like, and you know the one teacher is sitting there like, [in a hurry] 'cause they've been at school all day. I'm trying to read, and it's like, 'Do you have any questions,' well it can be an intimidating thing. (Parent Ta; 1:734)

In other instances, professional behavior reassured or encouraged parents, making them feel more comfortable and confident working with that professional or team.

> …my daughter, she's in the SLC [special education resource] room and she's in the regular ed room. And she wants to call her SLC teacher on the weekend. I'm like,

you know, I know there's a bond. And like the other day, when she called me to set

up the meeting, she's like, 'I haven't talked to you in a while, how are things going

you know. And I feel like I can go up there and talk to her. When I go to the school,

I don't go to the office and talk to them or the principal or whatever, I'm dealing

with the teacher directly. (Parent Ta; 4:80)

As mentioned previously, *professional behavior* links to *system characteristics.* (See

Figure 11.)

Participants expressed the importance of *flexibility* from professionals in their

approach to developing their child's IEP:

And the thing is they can't just be knowledgeable about the educational system.

They have to be able to go outside the box. Because our children don't work inside

the box. You have to literally think outside the box for them in order for them to

grow. (Parent N; 4:30)

Parents also described occasions where a lack of flexibility frustrated the process:

They were reprimanding her for not returning the homework. And I was like, well

she can't do homework. I had to ask them to tailor something that she can come

home and do every single night. Because basically it was like, 'she doesn't have to

do it.' She needs to do something. She can do something. (Parent Ta; 4:44)

Professionals emphasized the *flexibility* of the IEP in meeting the needs of the child:

I think they [parents] also need reassurance that just because we put this in the IEP

now, doesn't mean that a month from now we can't meet. (Professional Ca; 2:50)

Figure 20.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of

Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code

Flexibility Associated with Professional Behavior, Monitoring Progress, and

Communication Codes.
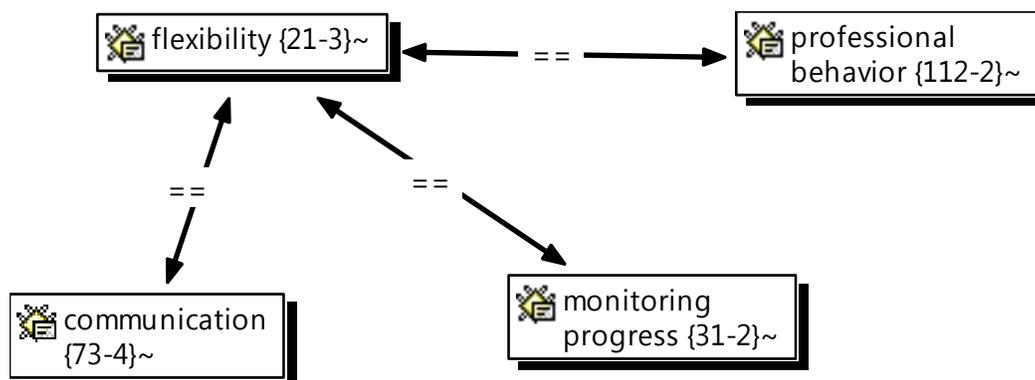
Flexibility links to *professional behavior,* as the degree to which a professional behaved

flexibly often influenced how a parent perceived the decision-making process to function.

Flexibility also links to *communication* and *monitoring progress.*

Figure 21.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Monitoring Progress Associated with Uncertainty and Flexibility.
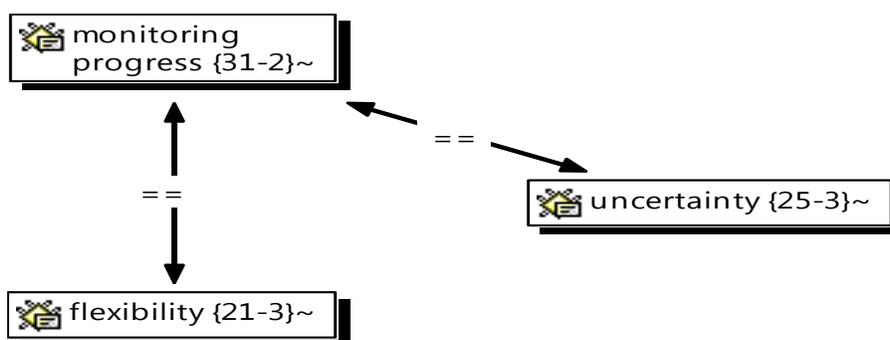
Parents reported that *monitoring progress* was necessary when dealing with the *uncertainty* that lies ahead for their child and the *flexibility* that is needed to create a successful IEP. They said monitoring progress closely was important to see how s/he would respond to different situations and demands. Parents also reported the need to monitor the progress of the relationship with school professionals.

> If you can see where that child is moving forward, then what you're doing is working. But if you don't see any progress of the child, then I think the whole team needs to be on the same page. (Parent N; 7:63)

Balance was another code that initially emerged through discussion with professionals. It refers to striking the balance between different needs and strengths of a single child or different opinions of team members, being able to balance the needs of one student with the needs of many students, and balancing the needs of the child with district

policies and procedures.

> I think presenting the pros and cons of decisions as we're talking about them. Okay,
>
> what are the benefits of being in general ed for an hour a day, what are the
>
> concerns? And kind of talking about those things with parents so that they
>
> understand both sides of it. And then, kind of talking as a team well what do we
>
> really want to do for the child? (Professional Ca; 2:260)

This quote also illustrates the linkage between *balance* and considering *child*

characteristics.

Figure 22.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Balance Associated with Child Characteristics.

balance {10-1}~

= =

child characteristics {131-8}~
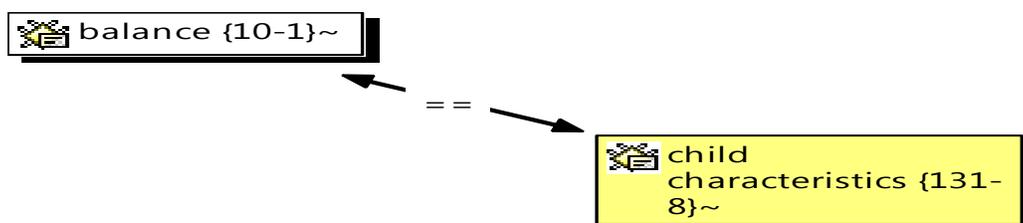
Facilitating factors were described as factors of relationships, experiences, or characteristics of people that made the decision-making journey a smoother ride for parents. *Facilitating factors* included (a) *advocate,* (b) *communication,* (c) *relationship,* (d) *support system,* (e) *parent knowledge,* (f) *early intervention/proactive,* (g) *persistence,* (h) *success in the past,* (i) *mutual responsibility,* and (j) *approach.* See Figure 23 for a visual representation of the Facilitating Factors Code Family.

Figure 23.

Codes within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Facilitating Factors Code Family.
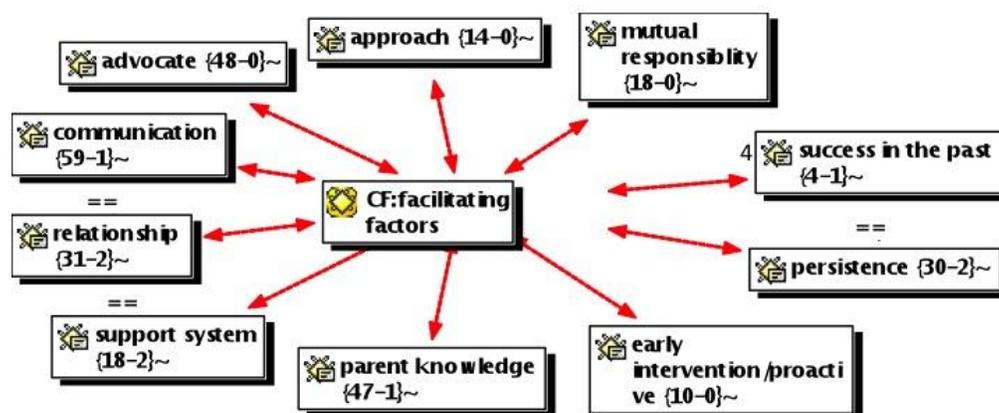
Having or being an *advocate* was identified by participants as a factor that made the decision-making process easier for parents. Parents described teachers or other professionals who spoke up on behalf of their child, out of a concern and care that the child achieves his/her maximum potential:

> I feel like, the teacher at the [previous] school district was a big advocate for my son. I mean, she just knew him, she knew how to get him straightened out, and just was a big, big advocate. So I think a lot of it has to do with how much the teachers really care about your child and how concerned they are about them achieving and

succeeding. (Parent Te; 1:152)

I do believe that, it has to be the teacher, the support of the teacher. She's not only

supporting [my son], but she's supporting me as well. (Parent N; 1:164)

In other instances, parents were the advocate, seeking out and speaking up for what they

thought their child needed to be successful.

…when we were in [other town] they wanted to move her into a program where

they learn life skills. We had to fight the district to keep her in her school because,

myself and the teacher, we were like she didn't really need this. I was like, 'I can

teach her that at home. I'll teacher her how to tie her shoes, stuff like that.' (Parent

Ta; 4:32)

One parent described her decision to make informational "business cards" to hand out to

people when her son had behaviors in public places. She told the group about the content of

the cards:

Hi, my son has autism, and if his behavior is inappropriate, this is the reasons why.

And I gave the Autism Speaks, www.autismspeaks so that they can read about it.

(Parent N; 1:301)

When parents were asked how they see their role on the IEP team, one parent shared:

Making sure that your child is receiving everything that he could possibly get. Just

being an advocate for your child. (Parent Te; 1:660)

Figure 24.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Advocate Associated with Communication.
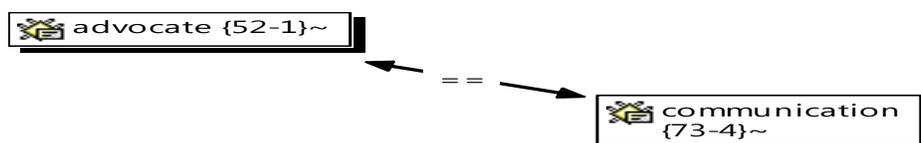

Whether parents had an advocate, or functioned as the advocate on their own, what was important for facilitating the process was that there was a voice speaking up and suggesting that the child needs more or the team could do better than what was initially on the table. For these participants, to advocate also meant to engage in *communication*, and thus those codes are linked to one another.

Communication is another facilitating factor identified by parents. *Communication* indicates the amount of and nature of reciprocal information sharing between professionals and parents.

I think communication is the most important thing. Between you and the teacher, and everybody that's working with your child. All the therapists, yeah. (Parent Te; 1:488)

Figure 25.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Communication Associated with Relationship, Flexibility, and Advocate.
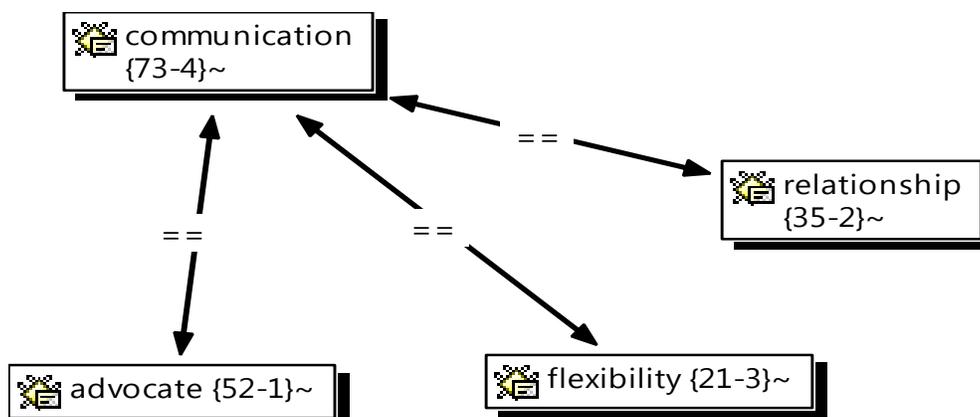
When professionals described communication, they also emphasized *flexibility* in that communication, and how that flexibility led to more positive experiences in decision-making.

> I've seen teachers put together kind of a survey: parent concerns, visions for the future, and stuff like that. Things that are on the IEP, but in a more parent-friendly way of doing it. So things aren't so rigid and so they're not put on the spot in a meeting. (Professional Ch; 2:349)

Communication can often contribute to *relationship*, described as the nature of interactions among adults involved with a child. The communication described above created a bond and understanding among those adults involved with a child.

Figure 26.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Relationship Associated with Support System and Communication.

```
┌─────────────────┐                    ┌─────────────────┐
│ 🖼 relationship │ ◄── = = ──►        │ 🖼 support system│
│    {35-2}~      │                    │    {23-4}~       │
└─────────────────┘                    └─────────────────┘
        ▲
        │
       = =
        │
        ▼
┌─────────────────┐
│ 🖼 communication │
│    {73-4}~       │
└─────────────────┘
```
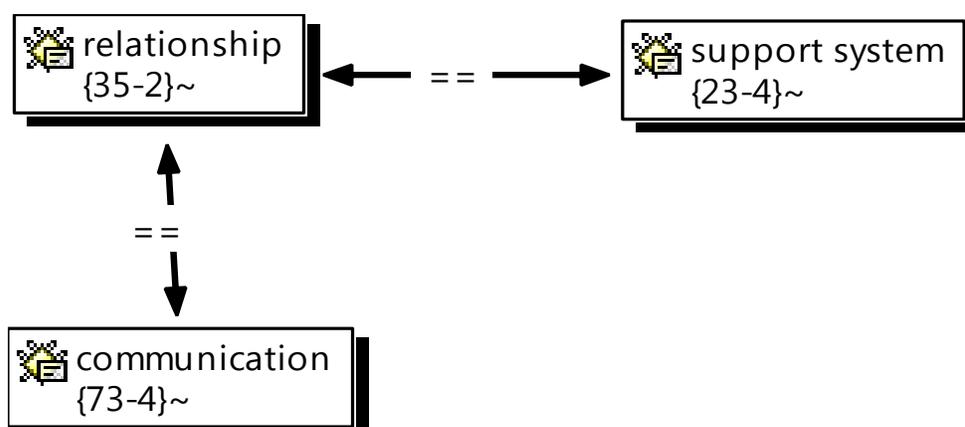
Relationships create the network for a *support system,* which also links to this code.

  The *support system,* made up of advocates (for this group, mostly teachers and some outside professionals such as doctors or psychiatrists) and other supportive family members, friends, or other parents, eases the way for parents in their decision-making. "I feel a little bit more at ease that, getting to talk to other parents of children with autism. You don't really get to do that very often." (Parent Te; 1:902). Professionals also recognized the impact of a support system: "If you don't have people right off the bat that are helpful and supportive, it's really tough to navigate that water." (Professional Co; 2:331)

Figure 27.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Support System Associated with Perspectives of Others, Autonomy, and Relationship Codes.
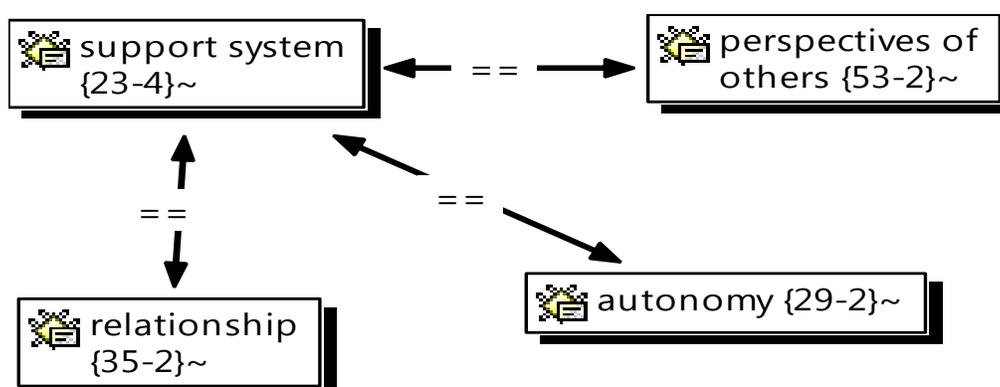
In the *support system*, there was the influence of *perspectives of others* in decision-making when considering what would be best for the child and family. When parents discussed the importance of a support system, the desire for *autonomy* was often intertwined, as they mentioned seeking out an autism support network in the county in which the school district was located.

> "…if we had that autism community, where the parents can get together and we can discuss some of these things, you know…" (Parent N; 1:267)

While parent knowledge was an important factor related to parents' experiences, when parents reported greater knowledge they also seemed to feel that their decision-making process was easier. Again, utilizing that unique expertise and knowledge about their child helped the parent to feel that their child's IEP was individualized to meet the priority needs of their child.

> "…not to say anything bad about the school or whatever, but I mean, they only

spend so much time with your kid. You're the one, you spend the most time, you

know, with that kid. You know what that kid is really able to do, and you really

need to step up and say, okay you know, no…it's okay for you not to always agree

with what they suggest." (Parent Ta; 1:682)

Parents reported that when their knowledge grew, they felt better about working with their

team. *Parent knowledge* links to *educating herself*, which at times also linked to *asserting*

herself as part of her *parent response*. As mentioned earlier, her *parent knowledge* linked

to and was influenced by specific *child characteristics*, her *individual experiences*, and

related to how she interacted with her *support system*. See Figure 8.

Parents described the importance of *early intervention* or being *proactive,* taking

action and seeking out services and supports for their child early, and trying to anticipate

what the future may bring.

I would have to say, from my experience, the best thing for me was that he was

diagnosed at 3 years old. And I think early treatment is the best treatment. And the

earlier they can start receiving therapy the better it is. (Parent Te; 1:433)

So now, we're looking and we're re-evaluating the IEP every 3 months because

there's no need for him to be sitting around you know. (Parent N; 1:656)

In this study*, persistence* meant continuing to try new things. Parents had to

maintain persistence in working with school professionals, while professionals who

persisted in trying new and different approaches facilitated progress for the child. One

parent stated, "I'm always looking for ways to improve, I'm always asking myself am I

doing everything that I could be doing…" (Parent Ta; 1:347) Other parents reported:

> You know, they wanted to baby her, and say, oh, you can't do that. And I'm like,
>
> oh, she can do that, and she will do that. And it's not a mean thing. I'm just like, I'm
>
> not accepting it because like, if she can do it, she's going to do it. (Parent Ta; 1:407)

> Yeah we've, they've tried many things on speech. They're supposed to be working
>
> on a computer machine, you know, to help get it out there, so I'm hoping, hoping
>
> something works. (Parent L; 1:184)

Figure 28.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Persistence Associated with Success in the Past and Asserting Herself Codes.
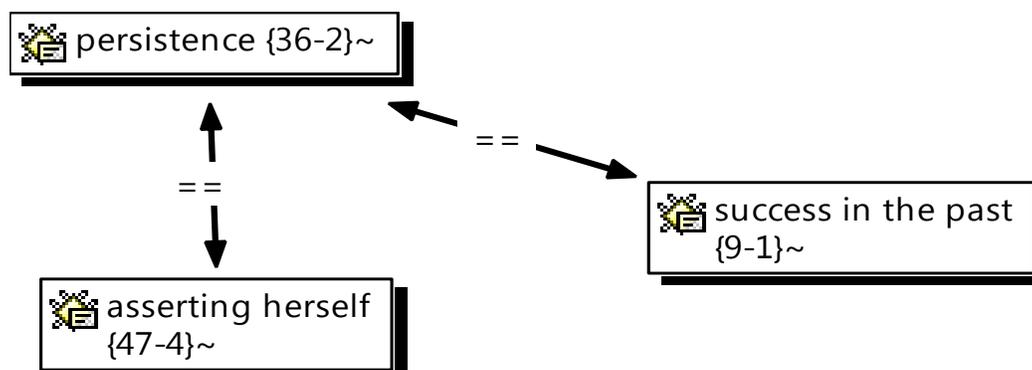
Codes linking to persistence include *asserting herself* and *success in the past*. In order to persist, parents often had to engage in *asserting herself.* When parents experienced *success in the past*, they often felt encouraged to keep up that *persistence*.

 Success in the past refers to instances where mothers described prior positive experiences. This success in the past often influenced their perception of the team and

encouraged them to keep working for their child. One parent described her success with her son's speech development: "My son went from not talking to being able to communicate everything! I mean, it was a tremendous change." (Parent Te; 1:273) Another parent shared how she used past successes to guide her work with the school team:

> One of the first things I asked at the initial IEP meeting coming out of a different district was what kind of program do you use to teach reading? Because I knew what she had used in the other school and the one they kept telling me is working, she's reading so good. (Parent Ta; 4:44)

Mutual responsibility is important to the support between home and school. When parents felt that both they and the school were taking responsibility as stakeholders in pursuit of positive outcomes for their child, this was a positive sign.

> She [daughter's teacher] will call me and say, 'Mrs. --, [your daughter] was doing this today' and it's not anything negative, like you know, like she was saying, she's just letting me know. And I'll tell her 'okay, well, we're going to work on that.' (Parent Ta; 1:168)

Figure 29.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Mutual Responsibility Associated with Communication.
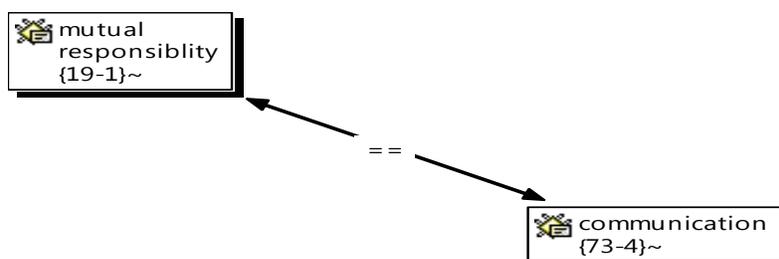
Mutual responsibility links to *communication*, as typically when people felt mutual responsibility, they were also communicating in discussing their roles and approaches.

Approach refers to people's ideas, mentality and behaviors toward the child with autism. Parents used this term to describe the way people considered and treated their child with autism. It often meant that they held the child accountable for behaviors, and set solid expectations for behavior.

> Wyandotte County does need my mother. She, when I moved from [other state], she was telling me, teaching me, the things that I was doing wrong. She was like, this boy ain't talking because you allow him not to talk. You know, you're going to have to do differently. And like, the whole not dressing issue, my mother just took his clothes, threw them at him, and told him, you're not leaving until you put your clothes on. See, it's a different approach, you know. (Parent N; 1:401)

Research Question 2: What are the decision-making needs of diverse parents of elementary-aged children with autism? The second research question sought to

identify challenges that parents experienced when making decisions about special education services for their child with autism. The themes that emerged from this line of questions were categorized as *challenges* and are described in the paragraphs that follow. Understanding these challenges, along with the other aspects of decision-making outlined in the model, helped guide us towards ideas for content and format of the decision aid tool.

  Challenges factor – Bumps in the road. When driving along a road, bumpiness along the way can cause one to feel unsteady which certainly makes the trip much less pleasant. Especially when those bumps are caused by potholes – or empty spots on the road. That is how these challenges emerged – areas that seemed to be lacking in the amount of control, knowledge level, support, resources, or personnel that parents encountered along their IEP journey. Those "potholes" identified by parents and professionals include (a) *lack of control,* (b) *lack of knowledge,* (c) *lack of resources*, (d) *lack of support*, and (e) *lack of personnel.* See Figure 30 for a visual representation of the Challenges Code Family.

Figure 30.

"Along the Road" in Grounded Theory Model of IEP Decision-Making for Diverse

Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools:

Challenges Code Family
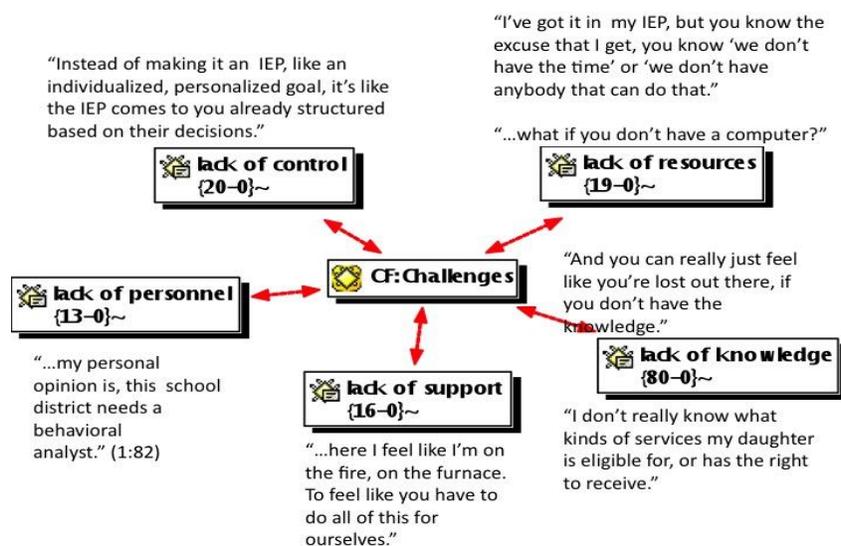
Parents reported feeling a *lack of control* about their child's IEP and the process of

making decisions to develop it. They reported feelings of the IEP being pre-established,

and that many meetings felt like a presentation of the IEP just seeking a stamp of approval,

rather than being something that parents and professionals developed together based on

mutual goals. Often, this pre-established IEP created a feeling that the IEP meeting was

rushed through, brushing over details of an IEP that appeared similar to other students

rather than individualized to meet a child's unique needs.

Usually when I go to the IEP meeting, they've already got everything outlined, as

far as educational stuff. They set the goals, and you know the guidelines that, you

know, the guidelines they're going to try to meet by the end of the quarter. So

really, I don't feel like I ever have anything to say about the educational decisions.

(Parent Te; 1:60)

…instead of making it an IEP, like an individualized, personalized goal, it's like the

IEP comes to you, it's already structured, based on their decisions… (Parent N;

1:82)

Figure 31.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Lack of Control Associated with Confusion.
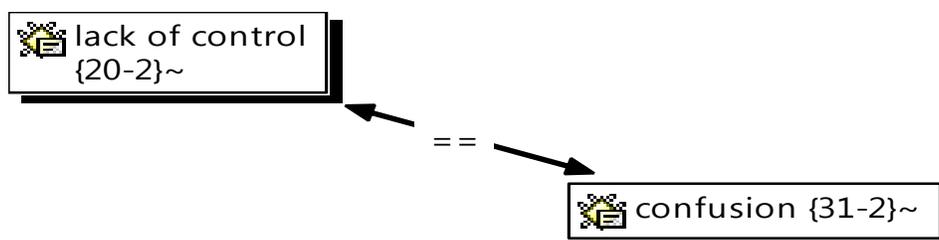
Parents reported a link from this *lack of control* to *confusion*, as they reported a lack of understanding of what was going on, who people were, or what their role on the team was.

Parents reported feeling alone and a *lack of support* from other people as they work through their decision-making. They spoke about wanting to connect and be supported by one another and by other people working for their child.

And it's kinda like, you know, I'm the only parent, I feel like I'm in it by myself.

I'm like, 'Am I the only parent in Wyandotte County?' (Parent Ta; 1:275)

Figure 32.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Lack of Support Associated with Overwhelming Code.
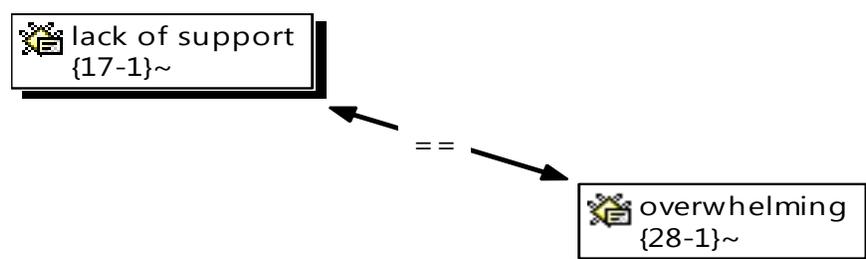
Without support, parents felt *overwhelmed* by the decision-making tasks at hand.

I mean, it's like, here I feel like I'm on the fire, on the furnace. To feel like you have to do all of this for ourselves. You feel like you have to literally put your dukes up. And you don't want to feel like you have to fight your child's school. (Parent N; 5:80)

The *lack of knowledge* code references both professionals' lack of knowledge and expertise in autism intervention, as well as parents' own lack of knowledge about available services in the district, their legal rights, or about current autism research.

They never broke it down for me, so I never could understand… (Parent L; 1:237)

And it's like, you really don't know what services are available in the district. (Parent Ta; 1:616)

…some of our kids with some of the general ed staff who maybe have limited

knowledge of special ed students, especially with students who have a diagnosis of

autism. Or, they think they had one student, 'so I know all about that.' But no,

everybody's different. I think that's kind of challenging. (Professional Ca; 2:100)

Figure 33.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of

Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Lack of

Knowledge Associated with Educating Herself and Confusion Codes.
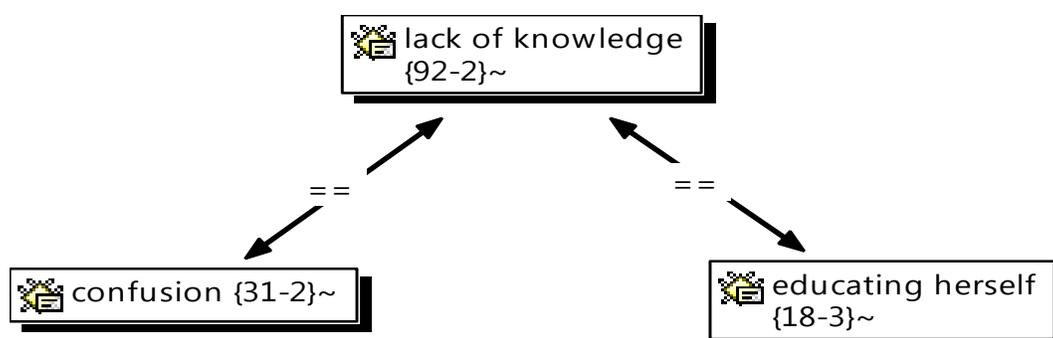
This *lack of knowledge* linked with *confusion* and the importance of *educating herself*.

You can really feel like you're lost out there, with nothing to grasp hold onto, if you

don't have the knowledge. (Parent Ta; 1:443)

Parents reported a *lack of personnel* in the district with more expertise and

knowledge around how to help their child as well as for further personnel available to

support their child, such as para-professionals.

My personal opinion is, I think this school district needs a behavior analyst, and the

district says, oh we do have a behavioral analyst, and when it comes down to it,

she's not able to do, what needs to be done. (Parent N; 1:82)

And you know, he has a para from [other school district], is he going to get a para.

And they're like, no, he's not going to get his own para. And I was like, 'oh really?'

(Parent N; 1:243)

Figure 34.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Lack of Personnel Associated with System Characteristics Code.
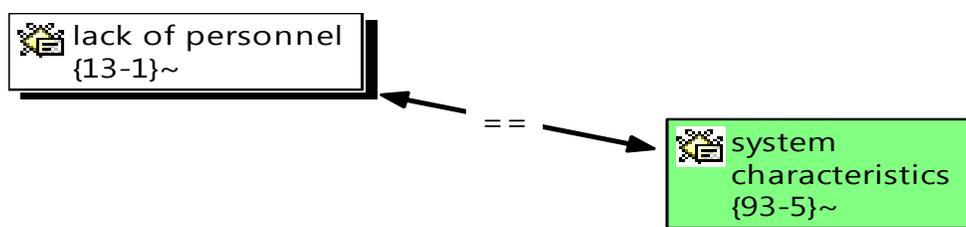
Because this code references issues within the school system, it also links to the *system characteristics* code.

Parents also reported a *lack of resources* available to them in the community and school district. This lack of resources was described in the form of programming, plans, or time. It also referred to parents' personal lack of resources such as money or technology.

I've got it in my IEP, but you know, the excuse that I get, you know, we just don't have the time, or we don't have anybody that can do that. (Parent N; 1:132)

Every time I ask, you know, what other services? And they're like, well you can look up online. (Parent L; 1: 622)

And what if you don't have a computer? (Parent Te; 1:624)

Yeah, and most of the time my computer's down, and I was like, come on y'all.

(Parent L; 1: 626)

Figure 35.

Links within a Grounded Theory Model of IEP Decision-Making for Diverse Parents of Elementary-Aged Children with Autism in Kansas City, KS Public Schools: Code Lack of Resources Associated with System Characteristics Code.
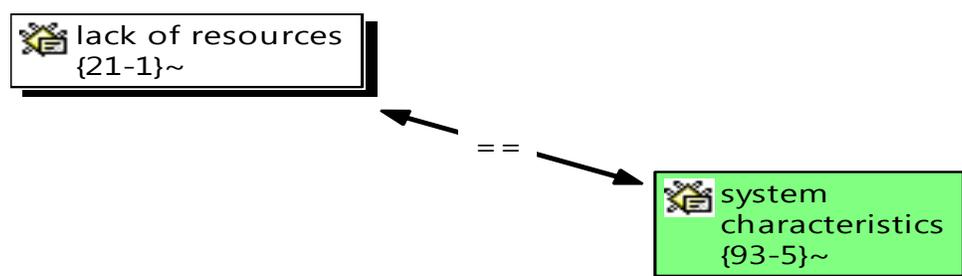
As this code references lacking resources within the broader systems of community and school district, it also links to the *system characteristics* code.

Research Question 3: What are the necessary components of a decision aid for diverse parents of elementary-aged children with autism? When exploring this third research question, several themes emerged from parents and professionals. Findings focused on the content and format of the tool. Parents and professionals emphasized the need for a tool that provided information and explanation for parent users. Format needed to provide opportunities for parents to provide input to the IEP and to be user friendly.

Design content. This code focused on the components that should be comprised in the decision aid, including information that should be a part of it. Parents and professionals

felt that the information should prepare parents to participate in the IEP meeting and provide input for the IEP that cover aspects of the child across home and school settings.

If you can prepare us for the IEP meeting then that's all we need. (Parent N; 5:6)

I think it needs to be a correlation between…you [parent] fill out what you do at home and we say what we do at school and then merge the two. Instead of trying to really focus in on it just being a school document. It needs to encompass all aspects of the child…Parents feel like it's just a school document. So they think 'I don't know really how he is at school, so I don't feel like I have a whole lot of input.' If it was more merged between home and school then parents would feel like they have a more important role because that's a part of the document. (Professional K; 6:46)

They also wanted a tool that provided explicit information about the contents of the IEP and explanation of those components.

We almost need a little booklet of key terms that parents need to know going in. (Professional K; 5:102)

Explain everything in detail. (Parent L; 6:101)

Or there might be a cliffs note that they would know ahead of time, that I'm going to ask you about concerns, I'm going to ask you about this and that, and when it says modality of learning, what does that mean? (Professional D; 2:355)

Design format. This code encompassed parent and professional ideas for how the

decision-making tool should look and function. For parents and professionals, it was very important that the tool provide parents the opportunity to formulate their input to share with their child's IEP team.

> There should be more input from parents. (Parent L; 6:52)

> This to me goes through what we want parents to think about going into the IEP. You need to make this your frequently asked questions. What do you need to think about going into the IEP? The tool almost needs to be IEP based because that seems to be the most confusing. (Professional K; 6:90)

It was also critical that the tool be user friendly, using language that was easy for parents to understand and visually appealing, with colorful sections that made it easy to follow. "Be more user-friendly. "(Professional K; 2:392) "Do it in bright colors and make it nice and useful. Black and white, no." (Parent L; 6:103) Based on prior parent discussion of the challenges of computer and internet access, a paper booklet format was chosen rather than a computer-based format.

Components of the decision aid. The following paragraphs describe components of the decision aid. Similarly to the grounded theory model, the decision aid follows a travel theme, formatted with components that correspond to a road map with street signs and traffic lights that guide parents through their IEP and provide the opportunity for parents to formulate input for each stop on the map. (See Appendix B for the Decision Aid).

The tool is designed to be consumable, with space for notes and ideas to be written

in as needed for each section. The sections are ordered to follow the sequence of sections of

an IEP from the Kansas City, KS public schools. There are also divider tabs placed to

identify where each section begins, for quick reference and in such cases where the IEP

meeting discussion may not follow the linear route of the IEP layout. Each section of the

guide includes a page with the street sign, a brief description of the purpose of the section,

a way to gauge one's concern about that area of the IEP through the use of a traffic light,

and prompts for planning next steps. There is also a *Terms to Know* section designed to

define some of the terms parents may hear when discussing that section of the IEP. The

Questions to Think About section lists questions parents may want to ask themselves about

that section, as identified by Advisory Board members. Some sections also include a

second page that includes the similar title, description, concern gauge, and next steps

planning, but additional sections are also included regarding people to know and services

to know. The *People to Know* sections are included to describe team members who

typically may be involved, have information about a particular area, or who may discuss

the area during the meeting. Listing these providers also gives parents an idea of who they

may want to speak with if they have specific concerns about that area of functioning.

Another component that may be included as part of the second page in a section is *Services

to Know*, which describes common services that students may receive to address needs in a

particular area (e.g. occupational therapy services may be listed here for the IEP *health and

physical status* section).

> **Title/Street sign**. Similarly to a street sign one would encounter on a drive, the

street sign/title of each page denotes the section of the IEP to which it refers. The green

background with white print mimics that of a street sign typically seen on streets everywhere. The title provides a means to navigate the guide as it corresponds to the order of sections in the district IEP.

Description. The next component refers to a brief description of the information that typically is included in the corresponding section of the IEP. For example, for the "Strengths/Preferred Learning Modality" section of the IEP, the decision aid contains a single sentence that summarizes the intent of the section in the IEP.

Terms to know. This component is essentially a brief, mini-glossary of important terms that parents may hear or read as part of that section of the IEP. These common and/or important terms are listed and defined. Every term listed in this section is also listed in a comprehensive Glossary of Terms (see below) that is provided at the end of the guide.

Questions to think about. The section titled "Questions to Think About" provides prompts for parents to consider when approaching each topic with their IEP team. Most questions were formulated based on feedback from parents and professionals as well as from focus group themes. Questions encourage parents to prepare to provide input on the section when they are in the IEP meeting, by asking parents about information from the home context and their personal experiences and knowledge related to specific aspects of the child, such as their communication style, social interactions, or other behaviors. Space is left for parents to write in their ideas, or to generate more questions of their own.

Concern gauge/Traffic light. The Concern Gauge/Traffic Light section provides a way for parents to gauge the importance of this area to their child's education and progress. Red indicates high concern (referencing the signal for stop – indicating the need to stop and

consider what needs to be done for this section), yellow (indicates a mid-level of concern, such as the signal to proceed with caution) and green represents a low level of concern (corresponding to the traffic signal indicator of green – to pass on through without needing to stop).

Next steps/Directions. From the rating parents provide on the Concern Gauge, they may choose to take further steps to address this concern. (Corresponding to the travel analogy, this may be the directions parents decide to follow to get to their destination.) Parents may choose to identify somewhere from which they can gain further information, a person that they wish to talk with about their concern, or they may feel that they want to formulate a response or idea to share with the IEP team about this area. Room is provided on the page for parents to write down these ideas and any input they wish to share with the team.

People to know. This component may be included on the second page in a section of the guide as needed, depending on the area of the IEP being covered. The "People to Know" section lists people on the team (besides the parent) who would have information to share about that particular area of the IEP and the child's functioning. The types of providers are listed as well as what types of work they typically do with the child.

Services to know. This component lists common services that may be discussed in this section of the IEP. It is included to help to answer a common question from parent focus group participants: "What kinds of services are available for my child?" It is denoted in this section that while there are several services that may be listed, a child must be found eligible for the services and so should discuss any questions about eligibility with the

school team.

Provider contact list. The Provider Contact List is a blank table that allows the parent to fill in information specific to his/her child's team: names of providers, their role on the team, and a way to contact them.

Glossary of providers. Providers from all "People to Know" sections throughout the guide are listed here in alphabetical order. This component is color-coded to match the corresponding section of the decision aid.

Glossary of terms. Terms from all "Terms to Know" sections throughout the guide are listed in alphabetical order here. This component is color-coded to match the corresponding section of the decision aid.

Glossary of services. Terms from all "Services to Know" sections throughout the guide are listed in alphabetical order here. This component is color-coded to match the corresponding section of the decision aid.

Glossary of programs. This glossary lists the special education programs or classrooms in which students with autism may receive services in the school district.

Sources for the decision aid components. Material for the decision aid came from a variety of sources. First, codes, code families and their relationships from the grounded theory model provided a starting point for discussion with the Advisory Board. Feedback and input from the Advisory Board was incorporated into further iterations of the model as well as into components of the decision aid. Some of that input included suggestions for contacting other personnel from within the district to provide information about various sections of the IEP. Additionally, the International Patient Decision Aid

Standards were reviewed as part of initial brainstorming for the aid, as well as for review of

the decision aid content by this researcher. All of these components contributed in various

ways to the most recent iteration of the decision aid. See Figure 36 for a visual

representation of how these various sources feed into the composition of the decision aid.

Figure 36.

Sources for Design of the Autism IEP Decision Aid: Grounded Theory, Input from

Advisory Board, Other Sources as Recommended by Advisory Board, and International

Patient Decision Aid Standards.
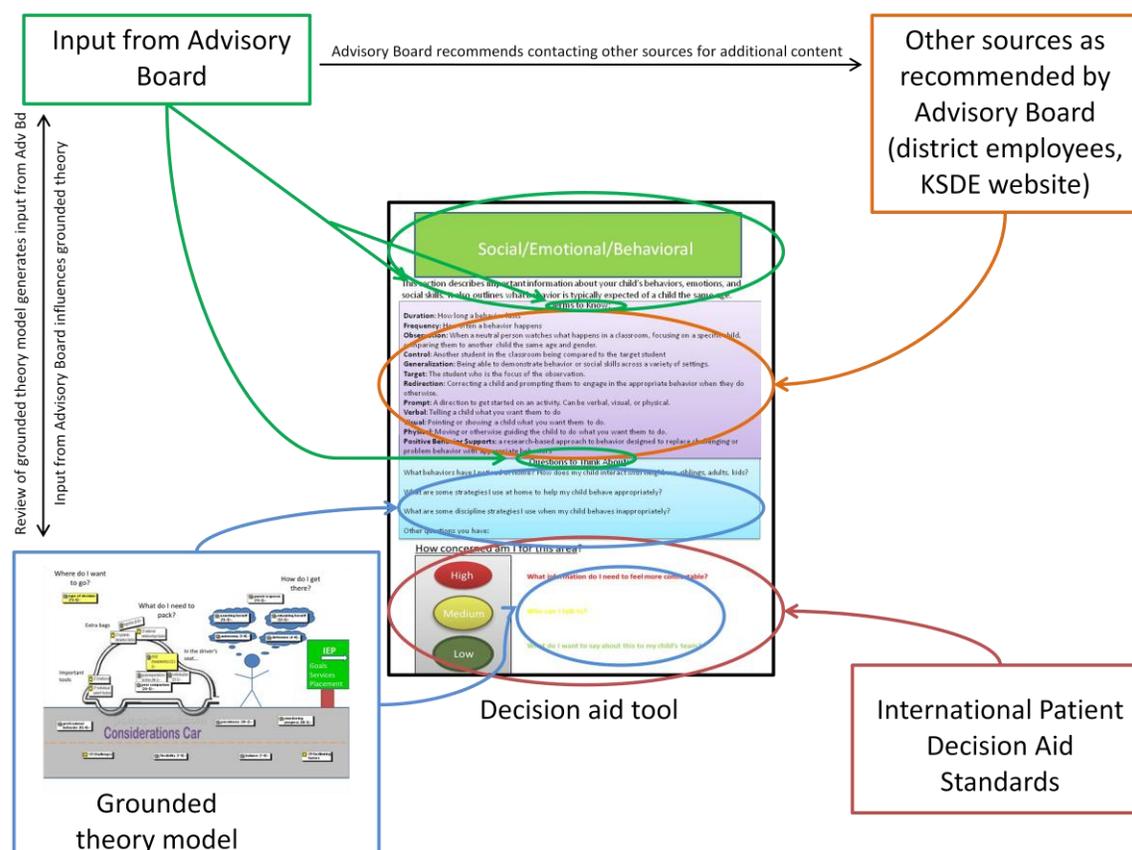
Grounded theory model. The decision aid addresses three of the challenges

identified by parents and professionals: *lack of knowledge, lack of resources* and *lack of*

control. Lack of knowledge is addressed through the provision of definitions for common

IEP terminology, programs available in the district, as well as an explication of services,

and the providers available for those services. Parents also identified a lack of resources,

which the decision aid addresses with information about who parents might choose to talk

with on their IEP team if they have additional questions, and provides them with prompts to help them consider where they might find more knowledge. The decision aid provides an avenue for parents to prepare and provide input about the IEP and their child's services, and in doing so hopefully decreases the lack of control that parents reported feeling about their child's IEP meeting and their decision-making.

The importance of recognizing individual child characteristics and orienting goal setting and services towards the unique needs of the child is incorporated into the section titled "Questions to Think About." In this section, common questions are listed pertinent to specific IEP areas, prompting parents to consider information that may be important to share or to seek out from the team regarding that area of their child's education.

To provide explanation of system characteristics that parents may consider when engaging in decision-making with their IEP team, a glossary of programs and providers is available for parents to use to understand which professionals may serve certain functions on their team. There is also a page in the guide that allows for parents to record team members, their roles, and contact information for each person on the team.

The *Next Steps* section of the decision aid, which includes questions about how parents may prefer to move forward, references some of the codes from the *parent response* code family in the grounded theory model. Parents may decide to educate or assert themselves by choosing to talk to someone at school about their concerns. They also may choose to educate themselves by gathering more information on the topic. They may also seek to talk with another parent or group of parents to establish their autonomy.

Input from the Advisory Board. As described previously, the Advisory Board gave

specific feedback about both the contents and format of the tool. Their recommendations included that for ease of understanding, the decision aid should follow the format of current IEPs in the school district and should provide information about each area including terms to know, people to know, services to know, and questions parents should ask themselves. Therefore, the order in which segments of the guide are introduced follows that of a district IEP. Parents sought explanations for each section, and wanted information about people involved in their child's team. Thus, the sections delineating terms, services, and people to know, as well as questions for parents to ask themselves were included. Professionals and parents thought it was important to make connections from school to home, to demonstrate the importance of shared knowledge and expertise across the home and school settings, guiding some of the content of the *Questions to Think About*. The Advisory Board also recommended that the format be colorful and use parent-friendly language, which influenced the format and illustration of the entire decision aid.

      Other Sources Recommended by the Advisory Board. Upon further discussion as an Advisory Board, suggestions were given for other resources to complete the information contained in the guide. Professionals and parents recommended contacting professionals with expertise in the various areas of the IEP to obtain more specific and thorough terminology to include in the *Terms to Know, People to Know, and Services to Know* sections, as well as to identify common questions parents may ask themselves when preparing to discuss each section. This included contacting a speech-language pathologist, music therapist and occupational therapist in the school district. These therapists were then asked for their input on a parent-friendly definition of the services they provide, common

terminology used by professionals in that discipline, as well as questions parents should

ask themselves as they consider the best next steps for their child with autism.

Correspondence with these individuals is included in Appendix E.

Discussion with the Advisory Board also indicated that there were some areas of

confusion even among the professionals serving on the Advisory Board about such terms

as Supplementary Aids and Services and what content should be included in that area of an

IEP. To assist in clarifying this question, the website for the State Special Education

website was consulted, to clarify definitions in the state special education regulations. This

input was included in the "Terms to Know" and "Services to Know" sections, as well as the

corresponding glossaries in the decision aid.

International Patient Decision Aid Standards. The International Patient Decision

Aid Standards were reviewed with Advisory Board participants as part of the initial

Advisory Board brainstorming meeting (see Table 1). It was agreed upon by participants

that it was difficult to present effectiveness probabilities or success ratios about various

types of curricula or interventions. They also agreed that a systematic design and

development process should be followed (parts of this process were accomplished through

this dissertation study), that information should be based on up-to-date information, and

that the tool should include language that was at an accessible reading level. They also

agreed that it should incorporate information about various options (see Terms to Know

and Services to Know), allow parents the opportunity to clarify and express their values

and provide some guidance in deliberation and communication (see Concern

Gauge/Traffic Light and Questions to Think About). The domain of establishing

effectiveness will be addressed in later studies with the decision aid. Parents also stated that sharing parent stories would be helpful in further aiding parent understanding of decision-making. Gathering further parent stories for illustration purposes for the aid will be a component of the next phases of design research with this tool. Parents gave feedback that there may be inconsistent availability of internet access for potential decision aid users, and so focus was given to creating a paper-based tool.

Chapter 5

Discussion

Summary

Diverse parents of elementary-aged children with autism and professionals with a variety of experiences working with children with autism report an abundance of types of decisions made by parents of children with autism in Kansas City, KS around their child's IEP. These decisions are influenced by a number of factors. These factors included (a) *child characteristics*, (b) personal *parent characteristics* and *emotions*, and (c) *systemic* and *external relationship factors*. Parents and professionals also described parents' perceived potential options for responding to the decision as they approached their child's IEP meeting. These options were: (a) *asserting herself*, (b) *educating herself*, (c) *deference*, or (d) *autonomy*. These possible responses may have been carried out singly or in some combination. Parents and professionals reported a number of factors that influenced the ease of their journey, including (a) *facilitating factors*, which made the journey go more smoothly, (b) *challenging factors*, or bumps and potholes in the road, and (c) other factors, which, depending on how they manifested themselves, could be positive or negative and which parents reported as being a part of their decision-making. These other factors included (a) *professional behavior,* (b) *flexibility,* (c) *balance,* and (d) *monitoring progress.*

Parents reported a need for knowledge, support, and guidance as they discussed the lack of knowledge, support, resources, personnel and control they experienced in making decisions about their child's special education services. Professionals also recognized

these areas of need, an alignment of perspectives that was somewhat unexpected.

These findings, forming a grounded theory of parent decision-making for local stakeholders, link to a decision aid tool that is useful and meaningful. The decision aid aims to provide specific information and guidance to diverse parents of elementary-aged children with autism about understanding their child's IEP and the school system of which their child is a part. While the decision aid could not encompass and address every need or challenge experienced by parents, it fills a portion of the gap recognized by parents and professionals alike.

Interpreting Findings

Interpretive note. Typically, this discussion would place important findings from this study within the scope of existing research and literature. However, there is a paucity of research available specific to diverse parent IEP decision-making for their children with autism. In fact, in multiple searches of several online databases, no American studies on this topic have been located. In one paper, summarizing two dissertation studies conducted in the UK, the authors reflected on qualitative findings regarding parent experiences of working with their child's special education services team (Hodge & Runswick-Cole, 2008). One author's prior study focused on parents of children with a variety of disabilities and their work with their child's special education team, resulting in appeals to a governing body overseeing special education services, while the other author's dissertation focused on the experience of parents of children with autism as they went through the diagnostic process for their child with autism (Hodge & Runswick-Cole, 2008). These researchers then discussed their findings in combination to provide some insight into the

decision-making process of parents of children with autism in the United Kingdom. While the findings described in Hodge & Runswick-Cole (2008) were specific to parents working in a different cultural and policy framework than parents in my study, the paper was the closest work available that mirrored the work done in this dissertation. Because of the lack of available research on this topic, this discussion incorporates related, but not similar studies and literature in interpreting the findings from this study.

There are a variety of factors influencing IEP decision-making for diverse parents of elementary-age children with autism in the Kansas City, KS public schools. These factors include interactions between individual characteristics of the child and personal experiences and beliefs of parents. Parents in this study had a range of expectations, goals, and wishes for their child, based upon their child's unique characteristics, from being able to take care of personal hygiene and maintain appropriate behavior, to running a Fortune 500 company someday. This range of expectations is recognized in research with parents of children with autism and other disabilities as they consider long-term visions for future employment and community participation, as well as more specific expectations, such as for use of assistive technology (Ivey, 2004; Parette & McMahan, 2002). Participants also recognized personal and emotional characteristics that influenced their experiences in decision-making for their child with autism when working with their IEP team. These parent and child factors interact with the larger systems of school and community and the relationship dynamics involved in those systems. These factors and their interactions must be taken into account when working to develop partnerships between parents and schools. These results mirror findings from research and theory about understanding the

interactions of "spheres of influence" of the family, school and community when developing partnerships with families of children with and without disabilities (Epstein, 1995).

Despite the prolific presence of autism advocacy groups, the increasing awareness of autism among education professionals, medical professionals and the general public, and the availability of massive amounts of information on the internet, parents of diverse background in this study report that they are still missing an avenue for information that is locally and personally relevant to their experiences. They are still missing what they need to navigate their corner of the world. These findings mirror research with families of preschool-age children with disabilities indicating that parents continue to need an understanding of the IEP process (Hanson, Beckman, Horn, Marquart, Sandall, Grieg & Brennan, 2000). Parents in this study share similar concerns of parents of children with a variety of disabilities in their desire for clear definitions of terms, services, acronyms, and professional roles (Mitchell & Sloper, 2002).

While the professionals in this study recognized parent needs and wanted to make improvements in creating partnership in decision-making, they struggled with balancing the needs of one student with the needs of many, while working with limited resources. Professionals in the field must continue to think creatively about how to incorporate what is known from the literature and what we have heard from the participants in this study about what works to increase and enhance parent decision-making. This includes encouraging communication and the development of relationships among parents and IEP team members built on mutual respect and shared approaches to understanding and

advocating for the child. Researchers and trainers must support parents and those professionals working in the trenches by developing useful, meaningful interventions and resources that make their day-to-day collaboration in developing IEPs more effective and lead to better relationships and outcomes for children and their parents.

Significance

This study used a design research approach to the creation of an IEP decision-making aid for parents of children with autism in Kansas City, KS schools. It is the first known study of its kind that has created a locally credible, feasibly usable decision aid that facilitates parent IEP decision-making and that has been developed through a systematic process that incorporated methodology from design research in instructional intervention as well as literature from decision aid development in the medical community.

A major product of this work is a grounded theory model of IEP decision-making for diverse parents of children with autism in the Kansas City public schools. Qualitative work of this nature has not been previously conducted with this specific population and the professionals with whom they work, and provides valuable insights into the experiences of this group of parents and professionals. Findings from this study can now be woven into the existing framework of what is known and theorized about how parents make decisions when working with their IEP team. This model is unique in that it is grounded in the real lived experiences of a group of parents and professionals in a specific community, and not just based on the theories developed by researchers and authors.

These findings focus specifically on the nature of the process of decision-making of parents in working with their child with autism's school team to develop the IEP, the

document that drives a child's education experience. The IEP may be the most important and influential document to the education of and intervention for a child with autism, whose needs are often complex. This study provides insight into the factors important to diverse parent IEP decision-making for elementary-aged children with autism. The number of children with autism is rising, and understanding how parents engage in a decision-making process, beginning with this specific community of children and their parents, in order to better plan for their child's IEP will certainly impact the types of outcomes achieved for this group of children and the trajectory for their contribution as members of the larger society.

Parents and professionals describe the decision-making process for diverse parents of elementary-aged children with autism as a journey which is ongoing and cyclical. While the emotions parents experienced were for the most part negative (overwhelming, frustration, confusion, and uncertainty), parents in this study were still seeking to engage with team members in the hopes of achieving their goals for their child with autism. Despite reporting concerns regarding available resources, personnel, control, knowledge and support, participants in this study identified several factors that facilitated parent decision-making. The number of facilitating factors outnumbered the challenging factors they identified. Many of these facilitating factors were relational, suggesting that even in a district where personal and systemic resources were limited, a positive relationship consisting of mutual responsibility, communication, advocacy, persistence, and proactive planning could promote positive experiences. Participants in this study report that parents had a variety of challenging emotions and experiences, and report that parents respond

with mostly positive approaches, including seeking more information, asserting herself, or seeking autonomy. It is interesting that professionals initially identified the less active response of deference, although parents later echoed this possibility.

Another product of this work is the creation of a tool. This decision aid is based on the local needs of parents in one community. It can now be pilot-tested and further evaluated to understand its impact on parent knowledge, partnership, and other outcomes for elementary-aged children with autism in Kansas City, KS public schools. This product may also provide a model for other school districts or for use with families of children with other kinds of disabilities.

Relationship to Previous Research

Factors interacting. Parents described an interaction of a variety of factors at work in their decision-making. First, at the most personal level, parents in this study had a unique understanding of their child and the individual characteristics that influenced their goals, expectations and wishes for the child and sought individualized goals and services to help their child achieve those expectations. Parents and professionals also recognized that parents carried with them personal characteristics and emotions that influenced interactions with their child's IEP team. At another level, participants in this study recognized that parents interact with other members of their family and friend circles when deciding on the best next steps for their child. These relationship dynamics also influence decision-making. At another level, diverse parents of children with autism interact with systems of the school district and community. These layers of factors are similar to the micro-, meso- and exosystems of Bronfenbrenner's ecological systems theory

(Bronfenbrenner, 1992/2005). While Bronfenbrenner's theory focuses on the interaction of people and systems for human development, this interaction is mirrored in the interaction of parents, their children, and the systems in which they work. As participants described parents working within the school and other systems, influenced by the individual characteristics of their child, personal emotions and experiences, personal family ties and the influence of important others, they evoke Epstein's "spheres of influence," the interaction of the school, family, and community systems (Epstein, 1995). Parents in this study appear to be influenced by both the external and internal models of these spheres of influence. They discussed the impact of district and county programming (e.g. various types of classrooms available, lack of support networks and informational resources) as well as the importance of positive personal communication, interaction, and relationships with their child's teacher and team. When parents felt that they had positive communication with their child's teacher or IEP team, then "the whole relationship is going to flourish" (Parent Ta; 1:168).

Progress on partnership for decision-making. Parents still report feeling a focus on themselves as "recipients" of service, and the experience of the IEP simply being handed to them and the educational decisions being pre-fixed. This feeling of being a recipient of a service rather than partner in identifying and providing supports for their child indicates a sense of the power-over relationship, in which there is an unequal balance of power and the professional controls communication and resources (Turnbull, Turbiville & Turnbull, 2000). Parents report feeling like they are working on the school's terms, within the school's rules. This contrasts with the intent of IDEIA and its principle of parent

partnership, where parents are to be participatory in nondiscriminatory evaluation as well as IEP composition. IDEIA also states that parents are to be given the opportunity to participate in IEP meetings in a variety of ways, at a mutually-agreed-upon time and with adequate time to prepare. This finding also corresponds to Christenson and Sheridan (2001) and Epstein (2001) critiques of the relationship between schools and parents in formulating broader-based partnership among parents of children with and without disabilities and the wider school institution. It also parallels findings from Blue-Banning et al. (2000), in which findings from focus groups of Latino families and service providers working with Latino children with disabilities that included, but were not limited to autism recognized a disparity in the power balance between parents and professionals.

Parents in this study recognized that often they felt as though decisions or services were presented to them rather than having the opportunity to be more involved in decision-making. The findings in this study contrast with findings from Garriott, Wandry and Snyder (2000), who surveyed parents of children with a variety of disabilities that included autism, and found that 45% of respondents "always" and 27% "usually" felt that they were treated as an equal, respected member of the IEP team and 46% of respondents reported "always" and 24% "usually" feeling that they have been allowed to have ample, direct input in the formation of IEP goals and objectives for their child. Participants in the current study noted that when they had increased knowledge and awareness, they were more likely to participate in their child's IEP meeting and share ideas than previously. This reflects findings from parents who report positive experiences with their IEP teams in Garriott, Wandry & Snyder (2000) that they feel they are part of the team because they

have been contacted, consulted and informed of important information prior to the meeting.

Parents and professionals in this study are seeking more participation and collaboration with parents and the IEP team. While this collaboration is sought, participants in this study recognize that parents and professionals are still working within the parameters of available district and personal resources, reflecting a move in the direction of a "power-with" scenario of partnership for parents of children with disabilities and professionals described in the early childhood special education literature (Turnbull, Turbiville & Turnbull, 2000). A "power-with" approach incorporates collaboration between parents and professionals that works within existing system and family resources. This contrasts with a "power through" approach that involves not only parents and professionals, but other friends and community members, and empowers all participants to engage in a synergistic manner and move outside the box of existing services to create new and preferred resources for all members involved. (Turnbull, Turbiville and Turnbull, 2000)

Parents also identified facilitating factors that encouraged their relationship and participation in decision-making with their school team. Some of these facilitating factors align with work from Blue-Banning, Summers, Frankland, Nelson and Beegle (2004)'s dimensions of partnership. These dimensions of partnership were developed based upon focus groups and interviews with adults with disabilities, family members of children and adults with disabilities, and professionals working either as administrators or direct service providers with individuals with disabilities and their families. While this work was not a

model specific to parents of children with autism, Blue-Banning et al. (2004) attempted to identify "common themes across a wide range of cultural, geographic and socioeconomic points of view." (p. 170). These overlapping factors included (a) communication, (b) mutual responsibility, and (c) relationship. While specific terminology may vary from that work to the findings in this study, the nature of partnership was stable across aspects of both the model and themes from Blue-Banning et al. (2004). Parents and professionals reported communication as one of the foundational aspects of a positive decision-making relationship between parents and schools, which mirrors Blue-Banning et al. (2004): "The quality of communication is positive, understandable, and respectful among all members at all levels of partnership. The quantity is also at a level to enable efficient and effective coordination and understanding among all members." (p. 174) The mutual responsibility and importance of relationship described by participants in this study mirror three of the components of partnership outlined by Blue-Banning et al. (2004): (a) equality, (b) respect, and (c) trust. The theme of mutual responsibility, sharing of duties and accountability to support the child with autism reflects Blue-Banning et al.'s (2004) description of equality: "members of the partnership…feel equally powerful in their ability to influence outcomes for children and their families" (p. 174). Participants discussing their relationships that worked also touched on respect: "members of the partnership regard each other with esteem and demonstrate that esteem through actions and communications" (p. 174; Blue-Banning et al., 2004). When parents and professionals in this study described the importance of relationship and mutual responsibility to one another, they resonated with Blue-Banning et al.'s (2004) findings about trust: "members of the partnership share a

sense of assurance about the reliability or dependability of the character, ability, strength, or truth of the other members of the partnership" (p. 174).

Professionals and parents recognized parent strengths' in the valuable knowledge that parents have of what works for their child at home. Parents have a unique expertise in the specific nature of their child, his or her history and the contexts of which s/he is a part. This acknowledgement of parent strengths and as co-contributors to planning for intervention is also found in the tenet of "using existing family strengths and capabilities to access and mobilize family resources" in Family-Centered Positive Psychology (Sheridan et al. 2004; p. 9). Along with acknowledging that they have unique expertise, parents want to feel that not only can they share this expertise, but they also seek more control in the relationship they have with professionals. Dunst, Trivette and Deal (1994) recognize the importance of this increased control through empowerment. This also echoes the findings of British researchers Hodge and Runswick-Cole (2008) who state that "Those professionals who engage with parents as guides, experts on their children who can identify the skills as well as the deficits, are trusted and well received" (p. 645).

Parents in this study reported a number of challenges they experienced in decision-making, some in particular which reflect specific concerns in the literature. Parents reported a need for knowledge, recognizing that they lack important information. This recognition moves beyond Brantlinger's (1987) findings that parents had significantly low knowledge levels despite relatively high satisfaction levels with their child's special education services. Parent characteristics such as work schedules and parent experiences of a lack of resources mirror Gaitan (2004) and Harry (1992) in their critiques of a need for

more sensitive approaches and practices by schools to engage with parents facing cultural

or economic barriers. Parents' experience with pre-prepared, prescriptive IEPs in this

sample matches with Rock's (2000) critique of IEPs as formulaic and lacking

individualization. Participants in this study report a lack of personal resources for parents,

as well as a lack of resources at the district level; these lacking resources also influence the

degree to which parents and professionals are able to partner. Benson, Karlof and

Siperstein (2008), in a study of a range of types of involvement of parents of children with

autism, including attendance at school meetings, noted that socioeconomic status was

directly associated with the degree to which parents were involved with the school.

Participants in this study also recognized the challenge of a lack of personnel to provide

support and appropriate expertise and a lack of knowledge of parents themselves. In the

current climate of reduction in state and federal funding available to schools and to special

education, this issue does not appear as though it will be remedied at a systematic level in

the near future.

Parent decision-making process. There is no one theory existing in current

literature that fully matches the process of decision-making for parents in this study.

Components of the model presented here affirm aspects of other models and theories from

the decision-making literature. Parents report weighing multiple attributes of a decision

(e.g. child characteristics, personal beliefs, relationship with the classroom teacher,

perspectives of others). While parents do not formalize the process quite to the same

extent, their process is indicative of multiple attribute decision-making (Yoon & Hwang,

1995), which, while not a theory specific to decision-making of parents of children with

autism, recognizes that decisions are multi-faceted and that differing components and attributes of choice alternatives may carry different weights and priorities.

Other components of the IEP decision-making process for diverse parents of children with autism in Kansas City, KS public schools can be framed by Wisdom-Based Action (WBA; Turnbull & Turnbull, 2009). Particularly, parents and professionals in this study emphasized the importance of parents knowing "where do I want to go?" which aligns with the WBA tenet of identifying one's goals or having a vision. Participants also discussed parents utilizing trusted perspectives of others, which aligns with the identification and utilization of trusted allies (people whom parents trusted as having knowledge and working in the best interest of the child) in the language of the WBA framework. Participants also recognized parent beliefs or values, while understanding and weighing contextual factors, which also echoes the Wisdom-Based Action framework (Turnbull & Turnbull, 2009). Participants reported that parents frequently sought more information prior to going forward with a decision, another step in the WBA framework. Many components of the grounded theory model emerging in this study mirror the steps described by Wisdom-Based Action, although the sources of information reported by participants in this study were less extensive than those encompassed by the steps in WBA. While Wisdom-Based Action references research and policy among sources of information, parents in this study typically accessed other parents or professionals as their source of information. The component of the model noted as "parent response" also is similar to the component of the WBA framework that describes "choosing the best available next steps" in making a decision. (Turnbull & Turnbull, 2009) While not a

perfect fit, many of the steps in parent IEP decision-making in this study seem to correspond closely with the WBA framework. It may not be surprising to note these similarities, as WBA is one of the only prescriptive frameworks for decision-making from the special education field. It should also be noted that Wisdom-Based Action is a framework in general for decision-making for parents of children with disabilities, and does not describe the process specific to IEP decision-making, or specific to parents of children with autism (Turnbull & Turnbull, 2009).

The decision aid and IPDAS criteria. The preliminary decision aid tool corresponds to a majority of the quality criteria outlined by the International Patient Decision Aid Standards (IPDAS; Elwyn et al, 2006). The tool utilized a systematic design process, as outlined in the Method section, and plans for future development are underway. The use of a systematic development process is Domain 1 in the Standards (see Table 1). The decision aid also provides information about options (Domain 2) through the Terms to Know, People to Know, and Services to Know sections. The Questions to Think About, and Next Steps/Directions sections correspond to the requirement for guiding or coaching in deliberation (Domain 6). The guide also utilized plain-language that is parent friendly as much as possible (Domain 10), as evidenced by parent review and approval as well as its Flesch-Kincaid reading level of 9.7 (approximately 9th grade reading level). The tool is based on up-to-date information (Domain 11) from research and a variety of sources within the school district. One of the challenges encountered in designing the tool was the presentation of probabilities for treatment choices, as frequently the success rates for curriculum or other instructional programming are unknown. Another challenge is the

delivery of the decision aid on the internet. While this delivery option is not currently available, the current format reflects the preferences of parents who participated in design of the tool and who reported challenges with accessing the internet with regularity.

Implications

This research is the first work of its kind coordinating an approach from Design Research to obtain an understanding of IEP decision-making for diverse parents of children with autism in Kansas City, KS public schools. Considering that there is a lack of research in this area, this study lays the groundwork of a long line of potential research seeking to understand this group of parents' processes. It is the first study that attempts to obtain an empirical understanding, based in parent and professional report, of how this group of parents engage in decision-making processes specific to their child's IEP. It provides an initial framework for future work in the study of parent decision-making processes for the IEP for their child with autism. While this work focused on diverse parents of children with autism, some of the similarities found from this work and across the literature could indicate that these findings may be echoed in other populations. However, this needs to be further studied.

This study has important implications for practice. In practice, information for diverse parents of children with autism in the Kansas City, KS public schools should be made readily available in a user-friendly format. Professionals and parents working together on school teams should stay flexible in addressing concerns, and work to be individualized in meeting children's needs. Using this tool can facilitate the provision of increased information to parents in user-friendly terms, while also promoting flexibility

and individualization in the development of IEPs for children with autism. The decision aid could also potentially aid parents in their decision-making experience working with their IEP team, in such specific ways as increasing feelings of parent self-efficacy in working with their team, their level of knowledge around issues related to the IEP, and their comfort level in working with their child's IEP team.

As with many issues in education, legislation has the potential to greatly impact the way we do business in education. Directions for legislative advocacy could include seeking more support for parents of children with autism at the regional or district level, as parents report the need for more locally relevant information. This may mean considering how to structure or restructure the current Parent Training and Information Centers to be more locally focused in the parent support they provide, getting more to the specific issues experienced by families in differing regions or individual school districts. Legislation could also incorporate more flexibility in the ways in which parents and schools work together, such as more flexibility in scheduling, meeting format, or attendees, as participants in this study report that IEP meetings, their attendees, and the information presented in them can be overwhelming and confusing. Because participants in this study report a need for more support of parents of children with autism, recommendations for changes in policy may also include ways that LEAs could provide additional forms of emotional or informational support to parents of children with autism, through parent resource libraries, support groups, or local parent-to-parent connections. School districts may desire to implement policies for decision-making that incorporate parents of children with autism as decision-making members at an administrative level, giving parents more of

an understanding of the system in which their children are a part, and providing parents the opportunity to voice their concerns about programming for children with autism that they expressed in this study (e.g. lack of resources and personnel, a lack of expertise in behavioral intervention, and lack of parent knowledge of the programming and services available for children with autism).

Limitations

Parent study participants were limited to only mothers, meaning that fathers or other caregivers' perspectives were only shared secondhand if at all. Focus group membership numbers were at the lower end of the minimum required (4 or 5, rather than 6 to 8 members). Due to funding and logistical limitations, parents who spoke a primary language other than English were not able to be included in the study. This limits the representation of decision-making experiences from parents of children with autism who also come from diverse linguistic backgrounds. Language differences were recognized by professionals as a potential factor that influenced parent decision-making and interaction with their school team. More parent groups with a variety of types of caregivers could provide a richer description of experiences and thus, a more complete model of parent/caregiver decision-making for their child with autism. As for professional participants, primarily special education professionals were included as focus group members, with the exception of one principal who had teaching experience in general education. Incorporating the perspectives of general education teachers could provide a more thorough description of concerns and experiences of teachers from a general education point of view. As in the parent group, professional participants were all female,

so experiences of male professionals were not represented in this study. Future research undertaken with male education professionals could widen the scope of views represented.

Qualitative analysis and interpretation was limited to associational relationships. As this work is exploratory, relationships are identified, but not in a directional fashion. This limits findings to be a representation of relationships and factors in IEP decision-making for diverse parents of children with autism in the Kansas City, KS public schools, not a causal or prescriptive model for diverse parent IEP decision-making for their child with autism. As more research is conducted, these relationships could be further explored and the directional nature of some relationships could be established.

The focus of the tool specifically to autism is both a blessing and a curse. It is able to address specific questions that parents may have about terminology, services, or providers. However, there are a wide variety of children and families experiencing different disabilities who may also benefit from a decision-aid tool but for whom this specific tool is not appropriate.

The tool still needs to be evaluated for effectiveness, and any conflicts of interest would be reported in future publications or use of the tool. Additional parent stories are needed to incorporate into the tool as recommended by the IPDAS. These stories were not widely available for this iteration of the tool, but future development could include gathering of parent stories to incorporate in the aid. Review of the incorporation of the IPDAS standards in the tool was conducted by this researcher, which is a limitation. Review by an outside auditor of the tool using the IPDAS criteria is needed.

Information incorporated into the tool has not been validated beyond the opinions

of employees who were interviewed and contacted as a result of Advisory Board feedback. Information sources were specific to the local school district and state where this tool was designed.

While the tool is geared to address multiple needs recognized by parents and professionals, it does not address all needs identified in this study. For example, parents reported a lack of support and resources that cannot be addressed by this decision aid tool. While the tool cannot address needs across all areas, it targets knowledge and decision-making as an avenue to empower parents to tackle other areas of need. Other manners for supporting parents in decision-making, such as via a decision-making "coach" could be explored in future work.

Suggestions for Future Research

Future research could include additional focus groups with fathers, grandparents, or other caregivers, as well as with a wider array of professionals, to increase the breadth and depth of information garnered through interviews. Based on these perspectives, the model could change, as could the tool. Additional focus groups and in-depth interviews with other parents of children with autism in Kansas City, KS public schools could further establish directionality among the relationships specified so far in this research.

Now that a tool has been designed in partnership with key stakeholders and other sources such as district personnel and the IPDAS, the next step using Design Research methodology is to embark on the development process, which includes prototype testing (Bannan-Ritland & Baek, 2008; Middleton et al., 2008). This includes asking stakeholders and other parents to take the tool for a "test drive" and provide some initial feedback on the

utility of the tool. Using qualitative feedback from stakeholders who are testing pilot versions of the tool can inform needed adaptation for future iterations (Kelly, 2006). From this feedback, further iterations of the tool would be developed as needed, and the next iteration of the tool could be tested in larger-scale field trials. As the tool's iteration is stabilized, quantitative measures of parent and student outcomes could also be taken to assess the tool's impact on parent variables such as empowerment, perceived control, and satisfaction as well as student variables such as goal attainment, behavioral ratings, and academic performance.

This methodology could inform the design of other decision-making tools for disabilities such as learning disability, intellectual disability, attention-deficit/hyperactivity disorder (ADHD) or other special health care needs. Future research could explore other possible avenues for decision aids, such as through the internet, or through a personal relationship like that of a decision "coach." The decision aid approach to decision-making support could also be contrasted to the use of other kinds of support such as a more broad-based parent resource library or tutorial on the internet.

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Table 1. IPDAS Domains and Criteria Used in Review of Existing Education

Decision-Making Tools.

Domain 1: using a systematic development process	Domain 2: Providing information about options	Domain 3: Presenting probabilities	Domain 4: Clarifying and expressing values	Domain 5: Using patient stories	Domain 6: Guiding/coaching in deliberation and communication
Criteria 1.1: Decision aid has information about the credentials of the people who developed it.	Criteria 2.1: The decision aid describes the [educational situation] related to the decision.	Criteria 3.1: The patient decision aid presents probabilities using event rates in a defined group of patients for a specified time.	Criteria 4.1:The patient decision aid describes the features of options to help patients imagine what it is like to experience their physical, emotional, and social effects.	Criteria 5.1: The patient decision aid provides stories of other patients'' experiences.	Criteria 6.1: The patient decision aid provides a step-by-step way to make a decision.
Criteria 1.2: [Parents] were asked what they need to prepare them to discuss a specific decision.	Criteria 2.2: The [parent] decision aid lists the [programming] options.	Criteria 3.2:The patient decision aid compares probabilities of options using the same denominator.	Criteria 4.2:The patient decision aid asks patients to think about which positive and negative features of the options matter most to them.	Criteria 5.2:If stories are used in a patient decision aid, the stories represent a range of experiences (positive and negative).	Criteria 6.2: The patient decision aid suggests ways to talk about the decision with a health practitioner.
Criteria 1.3: Practitioners were asked what they need to discuss specific decision with [parents]	Criteria 2.3: The option of choosing none of the [educational] options (e.g. doing nothing) is included	Criteria 3.3:The patient decision aid compares probabilities of options over the same period of time.	Criteria 4.3:The patient decision aid suggests ways for patients to share [what matters most to them when] others are involved in the decision.	Criteria 5.3:If stories are used in a patient decision aid, the steps used to select these stories are described [in a reference section or accessible technical document].	Criteria 6.3:The patient decision aid includes tools like worksheets or lists of questions to use when discussing options with a practitioner.

Criteria 1.4: [Parents] who were facing the decision field-tested the decision aid.	Criteria 2.4: Decision aid describes what happens in the natural course of a health condition if none of the options is chosen.	Criteria 3.4: The patient decision aid describes the uncertainty around the probabilities (e.g. by giving a range or by using phrases such as ''our best guess is'').	Criteria 5.4: If stories are used in a patient decision aid, the steps that experts used to review the information contained in these stories is included [in a reference section or accessible technical document]	Criteria 6.4:The patient decision aid offers the option of working with a trained ''coach'' to help patients consider the options.
Criteria 1.5: Practitioners who counsel [parents] on the options field tested the decision aid.	Criteria 2.5: Decision aid has information about the procedures involved (e.g. what is done before, during, and after the procedure)	Criteria 3.5: The patient decision aid uses visual diagrams to show the probabilities (e.g. faces, stick figures, or bar charts).	Criteria 5.5:If stories are used in a patient decision aid, a statement that the patients gave informed consent to include their stories is included. [in a reference section or accessible technical document]	Criteria 6.5:The patient decision aid offers the option of working with a trained ''coach'' to help patients prepare to talk about the decision with a practitioner.
Criteria 1.6: Field testing showed that the decision aid was acceptable to [parents]	Criteria 2.6: The patient decision aid has information about the positive features of the options (e.g. benefits, advantages)	Criteria 3.6: The patient decision aid uses the same scales in the diagrams comparing options.		
Criteria 1.7: Field testing showed that the decision aid was acceptable to the practitioners.	Criteria 2.7: The patient decision aid has information about the negative features of the options (e.g. harms, side effects, disadvantages)	Criteria 3.7:The patient decision aid provides more than one way of explaining the probabilities (e.g. words, numbers, diagrams).		
Criteria 1.8a: Decision aid was reviewed by outside experts ([education] professionals) who were not involved in its development or field testing	Criteria 2.8: The information about [outcomes] of options (positive and negative) includes the chances they [may] happen.	Criteria 3.8:The patient decision aid allows patients to select a way of viewing the probabilities (e.g. words, numbers, diagrams).		

Criteria 1.8b: Decision aid was reviewed by outside experts ([parents] who previously faced the decision) who were not involved in its development or field testing

Criteria 2.9:The patient decision aid has information about what the test is supposed to measure.

Criteria 3.9:The patient decision aid allows patients to see the probabilities of what might happen based on their own individual situation. (e.g. specific to their age or severity of their disease).

Criteria 2.10:The patient decision aid has information about the chances of receiving a true positive, true negative, false positive and false negative test result.

Criteria 3.10:The patient decision aid places the chances of what might happen in the context of other situations (e.g. chances of developing other diseases, dying of other diseases, or dying from any cause).

Criteria 2.11: The patient decision aid describes possible next steps based on the test results.

Criteria 3.11:The way the probabilities were calculated is described [in a reference section or accessible technical document]

Criteria 2.12:The patient decision aid has information about the chances of disease being found with and without screening.

Criteria 3.12:If the chance of disease is provided by sub-groups [e.g., younger, middle-age, or older people], the tool that was used to estimate these risks is described [in a reference section or accessible technical document]

Criteria 2.13:The patient decision aid has information about detection and treatment of disease that would never have caused problems if screening had not been done.

Criteria 3.13: The patient decision aid presents probabilities using both positive and negative frames (e.g. showing both survival and death rates).

Table 1 (cont'd.). IPDAS Domains and Criteria Used in Review of Existing Education

Decision-Making Tools.

Domain 7: Disclosing conflicts of interest	Domain 8: Delivering decision aid on the internet	Domain 9: Balancing the presentation of options	Domain 10: Using plain language	Domain 11: Basing information on up-to-date scientific information	Domain 12: Establishing effectiveness
Criteria 7.1: The patient decision aid reports where the money came from to develop the decision aid	Criteria 8.1:If the patient decision aid is used on the Internet, it provides a step-by-step way to move through the web pages (screens) on the Internet.	Criteria 9.1:The patient decision aid makes it possible to compare the positive and negative features of the available options.	Criteria 10.1:The patient decision aid describes the ''professional standards for plain language materials'' that guided its development (e.g. Plain Language Association International)	Criteria 11.1:The patient decision aid provides references to scientific evidence used.	Criteria 12.1:There is evidence that the patient decision aid helps patients recognize that a decision needs to be made.
Criteria 7.2: The patient decision aid reports where the money came from to copy and distribute the decision aid.	Criteria 8.2:If the patient decision aid is used on the Internet, it allows patients to search for key words in the decision aid.	Criteria 9.2:The patient decision aid shows the negative and positive features of options with equal detail (for example using similar fonts, order, display of statistical information).	Criteria 10.2:The patient decision aid identifies the reading level at which it is written and the formula [method] used to determine the level.	Criteria 11.2: The steps used to select the scientific evidence (e.g. finding, appraising, summarizing) is included [in a reference section or accessible technical document]	Criteria 12.2:There is evidence that the patient decision aid helps patients know about the available options.
Criteria 7.3:The patient decision aid reports whether the authors of the decision aid stand to gain or lose by the choices patients make after using a decision aid.	Criteria 8.3:If the patient decision aid is used on the Internet, it provides feedback on personal health information that is entered into the decision aid. [e.g. the chances you may get a complication]	Criteria 9.3:Field testing showed that undecided patients felt the information was presented in a balanced way.	Criteria 10.3: The patient decision aid is written at a level that can be understood by at least half of the patients for whom it is intended.	Criteria 11.3: The patient decision aid reports the date when it was last updated.	Criteria 12.3:There is evidence that the patient decision aid helps patients know about different features of the options.

Criteria 7.4:The patient decision aid reports whether the affiliations of the authors stand to gain or lose by the choices patients make after using a decision aid.	Criteria 8.4:If the patient decision aid is used on the Internet, the website provides security for personal health information entered into the decision aid.	Criteria 10.4:he patient decision aid is written at a level no higher than grade 8 [or equivalent] according to a readability formula (e.g., 7 SMOG or FRY).	Criteria 11.4: The patient decision aid reports how often the information in the decision aid is updated.	Criteria 12.4:There is evidence that the patient decision aid helps patients understand that values affect the decision.
Criteria 7.5:If the patient decision aid includes stories of other patients'' experiences, it reports if there was some financial or other reason why patients decided to share them.	Criteria 8.5:If the patient decision aid is used on the Internet, it easy for patients to find their way back to the point they were at in the decision aid when they clicked on links to other web pages.	Criteria 10.5:The patient decision aid provides ways to help patients understand information other than reading (e.g. audio, video, or in-person discussion).	Criteria 11.5a: The patient decision aid describes the quality of the scientific evidence (e.g. quality of research studies).	Criteria 12.5:There is evidence that the patient decision aid helps patients be clear about which features of options matter most to them.
	Criteria 8.6:[If the patient decision aid is on the internet, it can also be printed as a single document (e.g., pdf document)	Criteria 10.6: Field testing showed that the patient decision aid was understood by patients with limited reading skills.	Criteria 11.5b:The patient decision aid describes the quality of the scientific evidence (e.g. quality of research studies) [including lack of evidence].	Criteria 12.6:There is evidence that the patient decision aid helps patients discuss values with their health practitioners.
			Criteria 11.6: The patient decision aid uses evidence taken from studies on patients that are similar to the patients who would use the decision aid (e.g. age, gender).	Criteria 12.7: There is evidence that the patient decision aid helps patients become involved in decision making in ways they prefer.

Criteria 12.8:There is evidence that the patient decision aid improves the match between the features that matter most to the informed patient and the option that is chosen.

Appendix A:

Codebook

All current codes

_____

HU: Dissertation
File: [C:\Users\Jess\Documents\Scientific Software\ATLASti\TextBank\Dissertation.hpr6]
Edited by:Super
Date/Time: 2011-09-27 21:09:33

_____

advocate
Created: 2010-12-01 22:18:22 by Super
Modified: 2011-07-26 17:10:14

Families (1): facilitating factors
Quotations: 52
Comment:
     This could be referring to what parents talked about, as far as having a teacher as an advocate.   The classroom teacher knew her daugther and spoke up for her and how she compared to the other students. This also seems like it could be coded as considering what is developmentally appropriate, a factor in the decision-making process. Parents can also be an advocate for their child. The second quotation in this code refers to a parent doing just that.

     ABBEY had this coded as support system - referring to having people who are advocates for parents and who encourage them to self advocate.

_____

age
Created: 2010-12-01 21:41:52 by Super
Modified: 2010-12-10 18:10:19

Families (1): demographics
Quotations: 7
Comment:
     demographic variable that describes the age of the child who is the focus of the parent's responses. (child with autism)

_____

approach
Created: 2010-12-11 09:31:41 by Super
Modified: 2011-06-10 11:33:11

Families (1): facilitating factors
Quotations: 16
Comment:
     This code refers to people's ideas, mentality, and behaviors toward the child with autism. "approach" is a term used by a couple of parents to describe the way people considered and treated their child with autism. It often meant that they held the child accountable for behaviors, and set solid expectations for behavior.

_____

asserting herself
Created: 2010-12-05 21:05:59 by Super
Modified: 2011-07-26 17:17:01

Quotations: 47
Comment:
     This code refers to the parent's attempts to have her ideas heard by the school personnel or other professionals. This could include disagreeing with their suggestions, stating a strong opinion, or making her own ideas heard.

_____

autonomy
Created: 2011-04-13 11:07:48 by Super
Modified: 2011-07-26 16:23:41

Quotations: 29

Comment:
  Parents talked about wanting autonomy,this desire to be independent and doing things on their own, without the school overseeing everything.
  *** Merged Comment from: autonomy (2011-04-29T09:17:20) ***
  Th is code refers to the mentality of the parents when dealing with school personnel. Many times, the mothers would use vocabulary like "they" and "them" instead of "we" or "us." Seems like an oppositional relationship instead of a team relationship.
  *** Merged Comment from: autonomy (2011-04-29T09:53:31) ***
  This code and quote is more about raising awareness of what autism is and how people should respond, moreso than a lack of knowledge about the specific characteristics of their child. When this quote occurs is really when the mothers are starting to get energized about coming together and becoming a force, an educational, supportive force for parents of kids with autism.

  4/15 Does this link to the new autonomy code? Does parents' desire to move forward as a force of their own relate to the needs that they see for education of other people in the lives of their child?
_____

balance
Created: 2010-12-22 10:41:09 by Super
Modified: 2011-07-26 17:03:50

Quotations: 10
Comment:
  balance is a new professional code. This balance can refer to striking the balance between different needs and strengths of a single child, as well as being able to balance the needs of one student with the needs of many students.

_____

child characteristics
Created: 2010-12-02 21:31:40 by Super
Modified: 2011-07-27 11:23:38

Families (1): child centered
Quotations: 131
Comment:
  This code refers to the specific features of children that would factor into a decision. Speech, behavior, these are the aspects of the child that would be important to consider when making a decision for your child with autism. cognitive capacity,   Abbey also noticed a vein of "reality" which we decided is "awareness," sort of a sense of being realistic and understanding the capacity their child, as well as the strengths and limitations/differences. These parents understood that their children had unique needs and characteristics, that don't have a clear cut answer, and that must be acknowledged as they work for their education.   That doesn't mean that they lower any expectations, it just means they have a different path to reach that expectation. Also, the code of "child response" fits within this. Merge it into this code.
  *** Merged Comment from: child characteristics (2010-12-05T20:48:49) ***
  The child will respond differently to different people. He sits and giggles when Mom asks him to do something, but school reports that he is working on something and should be able to do it. Combine this into "child's characteristics."
  *** Merged Comment from: child characteristics (2010-12-30T11:14:42) ***
  The acceptance code relates to parents accepting their child for who they are and understanding what their needs are in order to make better decisions about the child. This relates to child characteristics, in that understanding what hte child needs will (in these professional's opinions) lead to better decisions. Relates to Katie's comments about expectations and goals as well. There is also a touch of that awareness of reality that Abbey had coded in earlier transcripts. There's also an indication that acceptance is a process that takes time, that a parent has to work through in order to accept the child.
_____

communication
Created: 2010-12-02 21:07:48 by Super
Modified: 2011-07-26 17:29:38

Families (1): facilitating factors
Quotations: 73
Comment:
  Communication is the name of this code, as it describes the nature of communication that happens between

professionals and parents. It can refer to the communication that comes from the parent to the teacher, and from the teacher to the parent. Communication is   a factor that seems to be influencing the way decisons are made. Is it related/subform or superform to mode of receiving information/feedback? Maybe...

We think this may be somehow related to "her vs. them" in abbey's list of codes.

───

confusion
Created: 2010-12-01 22:44:09 by Super
Modified: 2011-07-29 17:08:58

Families (3): Emotions, role, emotional factor
Quotations: 31
Comment:
    This code refers to a challenge that this mom faces. She finds the IEP confusing. Some examples of how this might be confusing are....academics - saying a goal should met with ___ percent accuracy, out of X many data days. Goals, language in the IEP, people's roles on the team, services they provide.

───

consider context
Created: 2010-12-02 17:10:39 by Super
Modified: 2011-07-26 13:43:06

Families (1): systemic dynamics factor
Quotations: 31
Comment:
    This code refers to taking into consideration the context in which the child needs to be able to undertake a skill. This means considering the differences between home and school environments and why a child may have different needs or behaviors in different places. I see this as a factor to consider in the process of decision-making.

    12/21/10: As I'm reading the professional transcript, I'm also struck that timing seems to be a part of context to consider as well. D's comment that when he went to middle school they had to think about waht would be the best placement indicates the transitional piece that goes into play as part of context.

───

deference
Created: 2010-12-22 21:01:06 by Super
Modified: 2011-04-17 13:38:34

Quotations: 4
Comment:
    Jess created this code to describe the parent behavior one professional talked about in the initial 25% of transcript from professional groups. In thinking it over, I think it would fall under parent response and family characteristcis. Deference refers to deferring back to professionals and their recommendations, going with what they suggest.

───

demographic
Created: 2010-12-01 21:37:35 by Super
Modified: 2010-12-10 18:10:18

Families (1): demographics
Quotations: 17
Comment:
    This code refers to the demographics of participants, including child age, years in the IEP process, gender, years in the district.

───

design content
Created: 2011-05-04 13:09:08 by Super
Modified: 2011-06-16 10:25:11

Quotations: 165
Comment:

This code describes ideas for content of a decisoin-making tool, including information that should be a part of it.

_____

design format
Created: 2011-05-04 13:08:59 by Super
Modified: 2011-06-16 10:25:14

Quotations: 25
Comment:
    Feedback/brainstorming for how the decision-making tool should look and function.

_____

early intervention/proactive
Created: 2010-12-10 09:15:11 by Super
Modified: 2011-04-29 10:29:45

Families (1): facilitating factors
Quotations: 11
Comment:
    This code relates to being proactive, and intervening early. Not always necessarily early intervention in the sense of
    early childhood, (although that's encompassed in this code), but also, taking action and being proactive when it comes
    to getting services or supports going for their child.

_____

educating herself
Created: 2010-12-05 21:05:59 by Super
Modified: 2011-07-26 17:17:01

Quotations: 18
Comment:
    This code refers to the mother's own taking of initiative to find out information. This could include researching
    treatments, autism, school choices, IEP process, law...etc."

_____

educational stuff
Created: 2010-12-01 21:53:56 by Super
Modified: 2010-12-12 11:21:39

Quotations: 4
Comment:
    Sees the IEP as focused on the "educational stuff" - she outlines further in her explanation of the goals and guidelines
    (I think she means benchmarks) to the goal. She says these are the goals "they" are going to try to meet. She's not a
    part of the goal development. She admits that she doesn't feel like she ever has anything to say about these
    educational decisions (goes back to pre-set).

    ABBEY: "her versus them" mentality is how she coded this quote and others like it. It's kind of a "they" mentality
    referring to how parent sees herself as different or separate. see Free Memo about us vs. them

_____

faith
Created: 2010-12-10 08:03:22 by Super
Modified: 2011-04-03 11:29:34

Families (1): individual parent factors
Quotations: 4
Comment:
    This code references the way that having faith or some kind of belief system leads to some people's interpretation of
    their child's disability and how they deal with it. Maybe a better code wold be values, to better encompass Ta's quote
    about her daughter, which she qualifies as not necessarily religious...

Parents interpret their child as a gift from God, as I'm sure many parents of nondisabled kids do. In a couple of the quotes, parents unpack this idea as if their child is almost a sort of teacher, there to teach parents, to teach and help others, and to inspire their parents to do the same.

_____

family considerations
Created: 2010-12-10 17:08:53 by Super
Modified: 2011-04-29 09:14:50

Families (1): systemic dynamics factor
Quotations: 25
Comment:
     aspects of family life that are influenced by or have influence on the child and the decisions parents are making.

_____

feedback on decision literature
Created: 2011-05-13 07:05:36 by Super
Modified: 2011-06-16 10:18:31

Quotations: 21
Comment:
     This refers to the confusion felt around the information presented to help them consider what should be a part of the decision aid tool.

_____

feedback on focus groups
Created: 2011-06-16 10:18:07 by Super
Modified: 2011-06-16 10:25:58

Quotations: 4

_____

feedback on model
Created: 2011-02-21 14:59:00 by Super
Modified: 2011-05-13 07:02:59

Quotations: 78
Comment:
     *** Merged Comment from: feedback on model (2011-04-17T10:42:40) ***
     This process code relates to feedback from the professionals about the process and factors models that we shared with them as part of the focus group.

_____

flexibility
Created: 2010-12-22 21:12:49 by Super
Modified: 2011-09-17 14:43:24

Quotations: 21
Comment:
     This code references the flexibility that professionals show, and the flexibility of the IEP itself and the decision-making process. We think that flexibility relates to professional behavior, as well as communication, as well as monitoring progress.

_____

Frustration
Created: 2010-12-03 18:05:07 by Super
Modified: 2011-07-27 11:37:53

Families (3): Emotions, role, emotional factor
Quotations: 18
Comment:
     This was a code that Abbey created to refer to parents' feeling of anger, disappoint, discouragement with the way their

child's IEP was written, with professionals' behavior, knolwedge, preparation, communication. Really they could have frustration with a lot of different things going on with their child. Parents often knew what they wanted, but had to push and push for getting it.

_____

gender
Created: 2010-12-01 21:41:52 by Super
Modified: 2010-12-10 18:10:18

Families (1): demographics
Quotations: 5
Comment:
demographic variable that states gender of the child with autism about whom the parent is reporting. all the parents in this study were mothers (females).

_____

goals/expectations/wishes
Created: 2010-12-10 08:17:53 by Super
Modified: 2011-07-27 11:24:52

Quotations: 56
Comment:
Having goals/expectations/wishes for your child is typical to every parent, but for these parents, the goals and expectations may be different, or the same, or even greater than parents of typically developing kids. These goals and expectations play a role in parents' interactions and relations with the school team.

12/22/10: This code also refers to the fact that some members on the team might have different expectations. For example, in paragraph 62, this teacher is talking about how she felt like parents didn't have the same expectaitons around academics that she would want them too. She felt as though maybe expectations were too low from parents sometimes...

4/15/2011: Parents discussed being annoyed by the concerns/visions for the future questinos on the IEP, because she felt like it would be obvious - that she wants her daughter to be doing what other kids the same age are doing, and that factors very much into the goals and expectations that she has for her child. LInk to peer comparison.

_____

grief process
Created: 2011-02-21 09:59:21 by Super
Modified: 2011-02-21 09:59:21

Quotations: 1

_____

has own ideas
Created: 2010-12-05 21:27:28 by Super
Modified: 2011-08-30 12:00:00

Families (1): individual parent factors
Quotations: 14
Comment:
This code refers to the mother's stating of her own ideas/suggestions on how to handle her child's IEP/treatment. This code is separate from "asserting herself" because the stating of an opinion was not always done during the IEP meeting/personnel conversation or given to the person responsible for implementing it.

_____

identifying with others
Created: 2010-12-03 17:35:18 by Super
Modified: 2010-12-22 20:47:36

Quotations: 6
Comment:
Abbey used this code to describe how parents seemed to relate to each other. Which coincided with Jess using the "Individual experience" code   to talk about how parents seemed to specify what it was like for them, rather than

assume that all parents felt the same or had the same situation. Parents also did a lot of confirming, relating with each other about similarities or parallels in their experiences and different situations.

_____

individual experience
Created: 2010-12-01 21:57:13 by Super
Modified: 2011-06-16 10:13:27

Families (1): individual parent factors
Quotations: 17
Comment:
  This mom (Te) is talking about what her individual experience has been. Most moms are beginning that way. I think this may be reflective of how each child's autism and the family's experience with it are truly unique.
  *** Merged Comment from: individual experience (2010-12-05T20:54:53) ***
  This mom gives the initial sense of a little sass, a little sense of humor here, while also playing to her feeling that she is experienced in working with and for her son's needs.

  4/3/2011: Each parent has had their own individual, unique, distinct experiences working with her child's team. This reflects how each child's autism and the family's experience with it are truly unique.

_____

individualize
Created: 2010-12-01 22:37:35 by Super
Modified: 2011-07-27 11:24:52

Quotations: 16
Comment:
  Parents have mentioned several times that they didn't like that htey felt like their child's goals were pre-set, and weren't individualized enough. Being individualized is sort of the opposite of being pre-determined. Although, being pre-set could mean they are still individualized. Abbey talked about parents feeling like it is almost a "cut and paste" for their child's goals. Or, the fact that they weren't consulted about the goal before it was written. What are they getting at? At the formulaic nature of what they for the IEP goals? Not sure if formulaic is the right word...

_____

lack of control
Created: 2010-12-01 21:52:21 by Super
Modified: 2011-07-27 11:37:53

Families (1): Challenges
Quotations: 20
Comment:
  Might want to call this something different. This gets at the IEP being pre-established, basically already set prior to the meeting, without mom getting to have a look at it. Mom doesn't feel like she's involved because it's already there to hand over to her when she gets to the meeting. Being pre-set means that also the team feels like they should or could rush through it because it is formulaic and not as individualized...

  ***ABBEY: called this lack of control - as pertains to her role on the team, being presented with something preset seems like it minimizes the control that a aprent would feel over their options.

_____

lack of knowledge
Created: 2010-12-01 22:15:09 by Super
Modified: 2011-07-26 16:15:40

Families (1): Challenges
Quotations: 92
Comment:
  This parent felt like one issue was the professional's lack of knowledge. The parent didn't feel like she knew this person or that the professional knew her daughter very well. So one type of challenge factor may be a lack of knowledge of professionals - and one type of knowledge that might be lacking is the personal knowledge of the child. Maybe this also speaks to the lack of individualization that comes up later in the discussion. This knowledge could also refer to parents understanding of their rights and what they may ask for and seek for their child. In one case, the parent considers vaguely an aspect of the law, or parents' right to request different accomodations, services, or other aspects of the IEP

for their child.

**ABBEY had this code too, and she also coded "frustration" as parents' reactions to those professionals' lack of knowledge, confusion.

_____

lack of personnel
Created: 2010-12-01 22:28:35 by Super
Modified: 2011-07-26 13:35:56

Families (1): Challenges
Quotations: 13
Comment:
    This code refers to parents' feelings of a need for people with more expertise and knowledge around how to help their child. They also refer to the need for further support for their individual child, such as in the form of a para-professional. Maybe this code should read, " lack of personnel support" or "lack of support personnel"? REname this Lack of Personnel -a more general description.

    ABBEY noted aspects of these quotes as being frustrating and confusing, as well as a feeling of lack of control over the situation.

_____

lack of resources
Created: 2010-12-02 17:42:56 by Super
Modified: 2011-07-26 13:36:50

Families (1): Challenges
Quotations: 21
Comment:
    This is another challenging factor - that there seems to be a lack of resources offered to parents. This can be in the form of programming, plans, time, or personnel.

_____

lack of support
Created: 2010-12-02 22:07:19 by Super
Modified: 2011-07-26 16:57:00

Families (1): Challenges
Quotations: 17
Comment:
    merge support and connection - its a lack of both/ that are closely related. This refers to how parents feel isolated. Merge lack of supprt and lack of connection - rename to "isolation."

    12/10/2010: in discussion and further analysis of the quotes for this code, we decided to rename it back to lack of support. We are still considering whether to add connection to this aspect thats lacking, or to find another name, but for right now, we like lack of support better than "isolation" we see moms talking more about wanting to connect and   be supported, rather than feeling singled out or alone   (isolated).

_____

logistics
Created: 2011-02-23 12:01:59 by Super
Modified: 2011-02-23 12:03:37

Quotations: 0
Comment:
    Refers to geographical or material necessities that impact parent participation in decision making. Includes distance family lives from school, bus stop, family's means of transportation, work schedules, number of people living in the home.

_____

mode of receiving information/feedback
Created: 2010-12-01 22:37:35 by Super
Modified: 2011-05-13 07:12:07

Quotations: 118
Comment:

      Maybe a more appropriate name for this code is "explicit" Parents want things to be explicit, to be broken down, step by step, to be explained clearly and in a parent-friendly way. ABBEY referred to this code/idea as "has own ideas" but we agree that explicit captures the concept better.
      *** Merged Comment from: explicit (2011-04-17T10:40:15) ***
      This code refers to parents' expressed preferences for how they want to get information. Parents are expressing the desire to get their information in a way that's meaningful, that they can see. Videotaping is a very concrete way to see the child and his/her behavior.

      ABBEY also had "has own ideas" - we think this could link together as parents frequently had their own ideas about hwo to collect data and present information, although not all of their ideas related to that.
_____

monitoring progress
Created: 2010-12-02 18:12:00 by Super
Modified: 2011-07-26 17:01:19

Quotations: 31
Comment:

      This code refers to the monitoring that parents reported was necessary. It appears that there are a lot of unknowns for these parents - about what the future holds for their child, how s/he will respond to different situations and demand, and for the relationship with school professionals.

      Jess is wondering about a different name for this code - something around monitoring progress and understanding there will be unknowns.
_____

mutual responsiblity
Created: 2010-12-02 21:21:28 by Super
Modified: 2011-07-26 17:29:38

Families (1): facilitating factors
Quotations: 19
Comment:

      We think mutual responsibility is important in the support that happens between home and school. THe first quote here refers to a teacher being proactive and a parent being responsive, which is preventative to having negative interactions.
_____

overwhelming
Created: 2010-12-01 22:47:27 by Super
Modified: 2011-07-26 16:57:00

Families (3): Emotions, role, emotional factor
Quotations: 28
Comment:

      This code speaks to a challenge that parents face - the challenge of being overwhelmed. In this case, she was specifically overwhelmed (and frustrated) that htere was so much information to go through and that she couldn't get through it all in such a short amount of time, and nor would she want to. Parents may feel overwhelmed by having an extensive amount of information, or by so many people working with their child, or with the different questions and concerns they might have about their child.
_____

parent characteristics
Created: 2011-02-21 10:59:46 by Super
Modified: 2011-09-27 18:48:25

Families (1): individual parent factors
Quotations: 10
Comment:

      behaviors, personality traits of parents, education level, work schedule that affect how they might interact with their

child's school team

_____

parent knowledge
Created: 2010-12-02 17:02:01 by Super
Modified: 2011-08-30 12:00:00

Families (2): individual parent factors, facilitating factors
Quotations: 51
Comment:
   This code refers to the idea that parents have their own expertise and knowledge about their child, in a unique way from the knowledge that professionals have. That "mother's knowledge."

   ABBEY has a code that relates to this code, "asserting herself" and "educating herself" - having to do with how parents made their desires known and also infomed themselves of options and possible interventions/strategies for their child. Another code that relates to this is "sense of what's right" - moms had their own innate ideas about what would work for their child. Consider renaming this to "intuition, combing, "sense..." with "parent knowledge."

   **maybe we should just add intuition to this code - calling it parent knowledge/intuition. because parents have accumulated expertise and knowledge of their child, as well as the ability to make judgements about or understand what they think will be good for their child. While I know that the purpose of this project is to help parents better understand how to make decisions using some explicit steps, we can't deny that there is also a component of intuition, or "going with your gut."

   **consider this code in relationship to support system. Are some of the things we coded here (Jess) overlapping with support system? How do we distinguish this code from the support system and from advocate?? Let's think on this....
   *** Merged Comment from: parent knowledge (2011-01-04T12:04:02) ***
   ABBEY had this code, we overlap a lot in this and what I coded as faith, and "approach"

_____

parent response
Created: 2010-12-01 22:11:09 by Super
Modified: 2011-07-26 13:16:20

Quotations: 89
Comment:
   This code refers to parent response when there are disagreements between the parent and school professionals. It refers to the nature of the disagreement and the parent's response to it.
   *** Merged Comment from: response when disagreement (2010-12-03T17:24:36) ***
   This parent responded to the pre-set IEP. She felt like she has the option to disagree, or ask things to be changed. Other parents didn't feel as heard when they wanted something different. This code refers to the parent response to the pre-set IEP, and not the professionals' response to a parent request.

   Rename this Parent Response***look up difference between response and reaction, we are stuck on the code definition....

_____

peer comparison
Created: 2010-12-01 23:13:15 by Super
Modified: 2011-07-27 11:24:52

Quotations: 27
Comment:
   Changed the name of this one to peer comparison instead of consider development. Because I think what parents are getting at is understanding what's typical, and aiming for that.
   *** Merged Comment from: peer comparison (2010-12-02T16:49:39) ***
   This code is related to a factor in the process of decision-making, things to consider as parents make a decision about what's right for their child. They mention themselves as well as other professionals comparing what the child needs or is doing compared to what other children need or are doing.

   THis is the same as ABBEY's idea behind her code of emphasizing normality.

   4/17/11: Updating this code to reflect the importance (to parents) of having their child be as close to their peers as possible. When thinking about not only the individual needs of the child, also considering what's typically expected of

peers.

_____

perceived parent role
Created: 2010-12-30 09:16:34 by Super
Modified: 2011-06-16 10:21:53

Quotations: 39
Comment:
   Should we call this perceived parent role? role perception? Tagged this because it seemed to relate directly to Abbey's
   research questions about parent role.

_____

persistence
Created: 2010-12-02 16:55:46 by Super
Modified: 2011-06-10 11:31:52

Families (1): facilitating factors
Quotations: 36
Comment:
   This code refers to the importance of continuing to try new things. This first quotation describes a parent's experience
   with prior school districts. She felt like they never gave up and were always trying new things to help her daughter make
   progress. THis code has more to do with professional behavior, and a parent's role in maintaining that persistence in
   their child's staff.

   THis relates to Abbey's codes of "success in the past" and "asserting yourself."

_____

perspective taking
Created: 2010-12-23 10:38:49 by Super
Modified: 2011-06-16 10:09:40

Quotations: 22
Comment:
   This code is indicative that the professional is understanding what parent concerns are, or what parents are struggling
   with. It also means that professionals may have their own kind of take, on what the issue is or what parents are dealing
   with. It affects how professionals see the parent role on the team or their capacity to be involved in different ways.
   **update 4/13/11
   We changed the name of this code to perspective taking to reflect the bilateral relationshp between parents and
   professionals recognizing each other's perspectives when working with the child. Especially with recognizing the effort
   and intention that goes into each other's work.

_____

perspectives of others
Created: 2010-12-02 21:44:24 by Super
Modified: 2011-04-13 12:42:44

Families (1): external relationships factor
Quotations: 53
Comment:
   *** Merged Comment from: perspectives of others (2010-12-02T21:45:07) ***
   This code is about seeking input and opinion from other people, besides professionals. This includes family members
   (like a spouse) or other parents, or consultants. ABBEY had 2 sort of "subcodes" within this area - referring to the
   "support system" that parents have available to them, as well as the phenonmenon of connecting and relating the
   perspectives of the other people in teh focus group (identifying with others).

   JESS 12/10: I'm noticing this word keeps coming up - "approach" - sometimes its about how others approach their kids,
   this approach that is like gently holding the kids accountable, and not allowing the disability to become an unnecessary
   crutch. Sometimes the moms needed someone with a different "approach" and other times it was the moms who had
   the "approach" and needed to show it to the school. This links back to an earlier quote from N about the different
   "approaches" of G's teachers he's had the past 2 years in the district. (quote 1:115)

_____

professional behavior
Created: 2010-12-02 17:27:59 by Super
Modified: 2011-07-26 17:01:19

Quotations: 112
Comment:
      This code refers to the aspects of professional behavior as they relate to parents' requests and work with them on
      different aspects of their child.
_____

relationship
Created: 2010-12-02 21:28:03 by Super
Modified: 2011-06-16 10:19:29

Families (2): facilitating factors, external relationships factor
Quotations: 35
Comment:
      This code relates to the relationship, a factor that influences the process of decision-making and that would be
      important to develop when working on making decisions.

      ABBEY's code of support system also links to this code. The nature of the realtionships in your support system.

      4/3/2011: The interactions among adults involved with a child. This can include the communication and conversations
      that happen, and the bond and understanding among those people.
_____

role change
Created: 2011-06-16 13:48:16 by Super
Modified: 2011-06-16 14:04:09

Quotations: 0
Comment:
      Parents' self-reported feelings and thoughts about how they relate to their team.

      THemes in this code that we noted:
      -communication increased with their team members
      -felt more confident/competent about communicating with their team
      -knowledge base increased as a result of talking with other moms and meeting with the advisory board
      -sense of support from talking to other parents about their children and their needs (normalization)
_____

success in the past
Created: 2010-12-05 21:29:44 by Super
Modified: 2011-06-16 10:01:53

Families (1): facilitating factors
Quotations: 9
Comment:
      This code refers to instances where the mothers listed successes they had had within the system in the past. These
      instances should be noted so we can look for themes of behavior (personnel and parent) that led to the success.
_____

support system
Created: 2010-12-05 21:30:46 by Super
Modified: 2011-07-27 11:50:24

Families (2): facilitating factors, external relationships factor
Quotations: 23
Comment:
      `This code refers to the mothers' mention of a system of support that has been helpful in the past or present. Most of the
      quotes found were discussing teachers that were especially helpful, doctors who were advocates, and family members
      who helped support parents.
_____

system characteristics
Created: 2010-12-02 22:35:04 by Super
Modified: 2011-07-26 13:36:50

Families (1): systemic dynamics factor
Quotations: 93
Comment:
    This code refers to characteristics of the school, the law, and other systemic factors that influence the way decisions
    are made by these parents.
_____

type of decision
Created: 2010-12-01 22:05:04 by Super
Modified: 2011-07-26 11:51:09

Families (1): child centered
Quotations: 82
Comment:
    This code refers to a kind of decision that parents reported having to make. This included things like working on social
    skills (having a peer buddy to work on social interactions), speech service time (asking for more), format for data
    collection/progress monitoring (videotape my child so I can see the behavior), behavior...
_____

uncertainty
Created: 2010-12-02 21:36:09 by Super
Modified: 2011-07-26 11:51:29

Families (3): Emotions, role, emotional factor
Quotations: 25
Comment:
    This code references the uncertainty that goes along with every decision. Just not being sure what the right step is to
    take, as you weigh the different options available to you and your child. ABBBEY also used this code to discuss the
    uncertainty that parents feel about issues they have dealing with the school - if interventions are being implemented
    consistently,for example.

    This links to the progress monitoring code.
_____

years in school district
Created: 2010-12-01 21:41:16 by Super
Modified: 2010-12-10 18:10:18

Families (1): demographics
Quotations: 4
Comment:
    demographic variable that relates to the number of years that parents had been in the school district in which this
    interview took place.
_____

years with IEP
Created: 2010-12-01 21:37:35 by Super
Modified: 2010-12-10 18:10:18

Families (1): demographics
Quotations: 5
Comment:
    Category within demographic - this refers to the number of years the child has had an IEP or been invovled with special
    education process.
_____

Appendix B:

IEP Decision Aid

A GUIDE FOR YOUR CHILD'S IEP

- **OVERVIEW:** This guide is meant to help you plan your child's special education services with your child's team. It's meant to be used before your meeting with your child's team. It would be helpful to have your child's IEP draft prior to the meeting so that you can review it and use this guide to prepare to discuss it.

- **Know YOUR RIGHTS:** You have the right to meet with the team at any time. You also have the right to review and revise the information presented in the IEP with your team. **You have many other rights, listed in your Procedural Safeguards. Ask for a copy if you don't have one.**

- **FLEXIBILITY:** The IEP is legal document, but it's also very flexible. What you agree for the plan now could change, based on your child's needs.

- **WHAT YOU'LL FIND INSIDE:** For each section of your IEP, there are **common terms** that you may hear, **questions you may want to ask yourself**, as well as a way to **rate your comfort** and/or knowledge of each area. There is also information about **people and services** you may hear discussed in each section.
- **WHAT YOU CAN DO:** You can **make notes** about information that you need, questions or comments you want to make sure you share in the meeting, and information about resources in our school district to help you understand the IEP process in KCK.

Navigating Your Child's IEP: A Road Map

Each section starts with the "street sign" or name of the part of the IEP. It follows a KCK IEP format.

Strengths and Preferred Learning Modality/Style

This section of the IEP describes different ways your child learns best and areas that are well developed for your child.

Terms to Know:

Auditory: hearing

Kinesthetic: hands on, using the body

Modality: method of learning

Questions to Think About:

How do I see my child learning at home? (watching, listening, or doing?)

What things does my child do well?

How can that help my child at school?

Other questions you have:
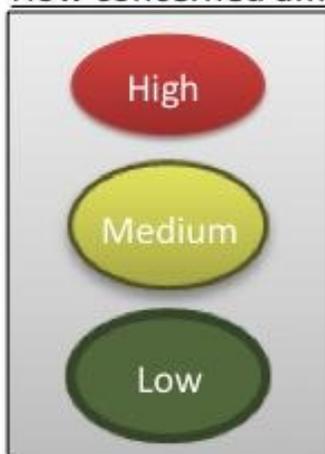
How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Parent/Student Vision of the Future

This section asks for your goals and visions for your child. It can be in the short term, such as what you want your child to learn over the next school year. It can also be long term, like what you want your child to be doing for employment, or where they are living in the future. These visions can help the team plan goals for your child.

Terms to Know:
There are really no terms to know in this area. You can fill it with your own thoughts and words!!

Questions to Think About:
How do I see my child's life in the future? What kind of job do I want him/her to have? Where does s/he live? Who does my child spend time with?

Which of these areas are important for my child to focus on for the next year: Health and Safety, Community Participation, Communication, Academic Growth, Social Interaction?

Other questions you have:

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Concerns of the Parent/Student

This section asks for your worries for your student and his/her education. These concerns can help to drive the goals that your child will work on for the next year.

Terms to Know:
There are really no terms to know in this area. You can fill it with your own thoughts and words!!

Questions to Think About:
What have I been worrying about when it comes to my child and his/her education?

Which of these areas has been a challenge for my child: Health and Safety, Community Participation, Communication, Academic Growth, Social Interaction?

Which of these will be important for my child to work on for this next year?

Other questions you have:

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Health and Physical

This section outlines important information about any illnesses, medication, medical diagnoses, or other information related to his/her health. It also outlines information about his/her physical abilities. This information is important because it can help the team to know about any special health or physical needs of a child.

Terms to Know:

Gross Motor: Large-scale motor skills, such as being able to run, walk, skip, jump, climb, and do the activities needed to get around the school building and participate in physical education and recess.

Fine Motor: Small-scale motor skills of fingers, hands and arms, such as holding a pencil, cutting with scissors, using a fork and spoon.

Visual Motor: the ability to simultaneously combine both vision and fine motor movements...i.e. hand-eye coordination

Nursing Plan/Health Care Plan: A plan that outlines services provided by a trained nurse.

Sensory systems: visual (eyes), tactile (touch), auditory (hearing), olfactory (smell), taste (mouth), vestibular (balance), proprioception (sense of where body is in space)

Sensory Input: information that is sent to our bodies from the 7 above sensory systems

Sensory Profile: An assessment that examines a student's sensitivity to different sensory inputs like sounds, light, touch, and other sensations.

Beery VMI: assessment that examines a child's ability for hand-eye coordination. How they can look at and imitate various shapes and designs

Beery Visual Perception: assessment that examines a child's ability to perceive similarities and differences in objects and designs (a subtest of the VMI)

Beery Motor Coordination: assessment that examines a child's ability to maintain fine motor control of the fingers when putting written work on paper (another subtest of the VMI)

Peabody: assessment that examines young children's developing motor skills in a variety of areas.

Sensory Diet: Ideas or suggestions of various sensory input to add to a child's day or ways to avoid or work around input that is disturbing to a child in order to help them function better in their environment

Sensory Seeking: A person that seeks out additional input through their day. They need to input to help them function better. (i.e. rocking, spinning in a chair, listening to certain music, tapping fingers, clicking a pen, etc)

Sensory Sensitive/Avoiding: A person who is sensitive to various sensory input or who goes out of their way to avoid input. It may disrupt their ability to fully function in their environment

Sensory Threshold: The level of input that a person needs to function at their best. Someone with a high threshold needs more input to reach that level and someone with a low threshold needs less input.

Questions to Think About:

What health or medical information is important for people at school to be aware of? Doctor's information, diagnoses, medication, or recent hospitalizations?

How are my child's gross and fine motor skills? What areas of concern should be noted?

How does this information affect what my son or daughter is doing at school?

Other questions you have:

How concerned am I for this area?

High

What information do I need to feel more comfortable?

Medium

Who can I talk to?

Low

What do I want to say about this to my child's team?

Health and Physical

There are important people and services to be aware of related to your child's health and physical status. Listed below are people you may meet or services you may talk about related to health and physical.

People to Know:

Adaptive PE Teacher: A physical education teacher who has special training in adaptive physical activities to meet student sensory and physical needs in a small group environment

School Nurse: A health care professional trained to work in a school setting and address student health needs in a school setting.

Occupational Therapist: Works with the student on fine motor skills and sensory needs related to education.

Physical Therapist: Works with the student on gross motor skills important to his/her education.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Nursing Services: Health care services that can only be given by a medical professional. May include changing a medical apparatus (like a colostomy bag), or feeding students through a G tube.

Occupational Therapy: Address a child's fine motor skill and sensory needs.

Physical Therapy: Address a child's gross motor skill needs.

Adaptive PE: Adapt typical physical education to meet unique sensory or physical needs that students have, working in a small group setting.

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Social/Emotional/Behavioral

This section describes important information about your child's behaviors, emotions, and social skills. It also outlines what behavior is typically expected of a child the same age.

Terms to Know:

Duration: How long a behavior lasts

Frequency: How often a behavior happens

Observation: When a neutral person watches what happens in a classroom, focusing on a specific child, comparing them to another child the same age and gender.

Control: Another student in the classroom being compared to the target student

Generalization: Being able to demonstrate behavior or social skills across a variety of settings.

Target: The student who is the focus of the observation.

Redirection: Correcting a child and prompting them to engage in the appropriate behavior when they do otherwise.

Prompt: A direction to get started on an activity. Can be verbal, visual, or physical.

Verbal: Telling a child what you want them to do

Visual: Pointing or showing a child what you want them to do.

Physical: Moving or otherwise guiding the child to do what you want them to do.

Positive Behavior Supports: a research-based approach to behavior designed to replace challenging or problem behavior with appropriate behaviors

Questions to Think About:

What behaviors have I noticed at home? How does my child interact with neighbors, siblings, adults, kids?

What are some strategies I use at home to help my child behave appropriately?

What are some discipline strategies I use when my child behaves inappropriately?

Other questions you have:

How concerned am I for this area?

High

What information do I need to feel more comfortable?

Medium

Who can I talk to?

Low

What do I want to say about this to my child's team?

Social/Emotional/Behavioral

There are important people and services to be aware of related to your child's social/emotional/behavioral status. Listed below are people you may meet or services you may talk about related to behavior. While these individuals may discuss aspects of your child's behavior, all people on the team are responsible for helping to address your child's needs in this area.

People to Know:

School Social Worker: Provides services to support your child's behavior or emotions. S/he may meet with your child individually or in a small group in a special education classroom or general education classroom to practice appropriate behavior, social skills, or emotional control.

Continuous Improvement Facilitator: Provides guidance and support to the team when students are having behavioral or academic concerns. This person typically has experience as a special education teacher.

Behavior Interventionist: May get involved if behaviors are complicated or extra challenging for the team and they want another person's expertise on working with kids with autism and their behavior.

School Psychologist: Professional with special training in assessment and behavior. May help gather data about your child's behavior or provide counseling services.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Counseling Services: Support from a specially trained social worker or school psychologist on a regular basis to address social, emotional or behavioral needs of your child. Counseling services may be provided in the general education classroom or in a special education setting.

Circle of Friends: A specially designed group where your child may work with other kids who don't have autism to practice social skills and communication in a playful and fun small group environment.

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Behavior Intervention Plan

A Behavior Intervention Plan may be necessary if your child's behavior gets in the way of his/her learning, or the learning of other students.

Terms to Know:

Does the behavior impede learning of the child or others? This question asks whether a behavior or set of behaviors interferes with a child being able to learn.

Behavior Intervention Plan: A plan that describes ways to support a child to engage in appropriate behavior, and how adults need to respond if a child behaves inappropriately.

Questions to Think About:

What behavior does my child display that could interfere with his/her learning?

What do I do to redirect or discipline my child when they misbehave?

What do I do to reinforce my child for behaving appropriately?

Other questions you have:

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Behavior Intervention Plan

When the team decides to implement a Behavior Intervention Plan, everyone who works with the child is responsible for helping to implement it.

People to Know:

School Social Worker: Provides services to support your child's behavior or emotions. S/he may meet with your child individually or in a small group to practice appropriate behavior, social skills, or emotional control. She may be a key person in writing and helping people at school to implement the plan.

Continuous Improvement Facilitator: Provides guidance and support to the team when students are having behavioral or academic concerns. This person typically has experience as a special education teacher.

Behavior Interventionist: May get involved if behaviors are complicated or extra challenging for the team and they want another person's expertise on working with kids with autism and their behavior.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Counseling Services: Support from a specially trained social worker on a regular basis to address social, emotional or behavioral needs of your child.

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Functional Behavior Assessment

A Functional Behavior Assessment (FBA) is typically conducted to understand reasons for why a child is behaving a certain way. Understanding these reasons helps the team to know how to help the child learn to behave appropriately.

Terms to Know:

Functional Behavior Assessment: Collection of information about a behavior to determine why it's happening and how to improve the behavior.

Referral: Information about what behaviors are happening and why they are a concern.

Interview: Perspectives about the child's behavior from people who know the student.

Antecedents: Things that happen prior to the behavior that make it more or less likely to happen.

Consequences: Things that happen after the behavior that make it more or less likely to happen.

Function: Why the child does the behavior.

Frequency Count: Keeping track of how many times a behavior occurred in a specific time period.

Time sample: Observer keeps track of very short intervals of time and the type of behavior that happens in each interval. A percentage of time spent on- and off-task can be calculated from this observation.

Scatter plot: A graph that represents how often different behaviors happen over time.

Motivation Assessments: Tools used to determine what types of things might motivate a child's behavior. Common assessments used in KCKPS include the Motivation Assessment Survey or the Dunn-Rankin Reward Preference Inventory.

Questions to Think About:

Why do I think the behavior is happening?

What makes my child more or less likely to do a behavior?

Other questions you have:

How concerned am I for this area?

High — **What information do I need to feel more comfortable?**

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Functional Behavior Assessment

The Functional Behavior Assessment helps the team to figure out why a behavior is happening. When the team figures out why the behavior is happening, they can know better how to teach the child appropriate behavior.

People to Know:

School Social Worker: Provides services to support your child's behavior or emotions. S/he may meet with your child individually or in a small group to practice appropriate behavior, social skills, or emotional control. She may be a key person in writing and helping people at school to implement the plan.

Behavior Interventionist: May get involved if behaviors are complicated or extra challenging for the team and they want another person's expertise on working with kids with autism and their behavior.

School Psychologist: May help with data collection and designing the FBA and BIP.

Continuous Improvement Facilitator: Provides guidance and support to the team when students are having behavioral or academic concerns. This person typically has experience as a special education teacher.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Counseling Services: The school social worker or school psychologist may work with the team to gather important information about the behavior. They also may provide services to support the child in carrying out the plan.

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Behavior Intervention Plan

The Behavior Intervention Plan (BIP) outlines what adults and the child will do to increase positive (desired) behaviors and decrease negative behaviors.

Terms to Know:

Baseline: What the child is currently doing.

Data: Information about the behavior, that could include a count of the behavior, rating of the behavior, school records, or information from an interview

Target Behavior: The behavior that we want the child to change.

Environmental Supports: How the environment will be designed to encourage appropriate behavior.

Reinforcement: Privileges, objects, or other events that encourage a behavior to happen more often.

Reactive Strategies: How adults respond to a child when he/she has inappropriate behavior.

Intensity: How severe a behavior appears to be.

Duration: How long a behavior lasts

Frequency: How often a behavior happens

Positive Behavior Supports: A system of intervention and prevention approaches to encourage appropriate behavior.

Visual Supports: Visual cues that help a student with staying on task and maintaining appropriate behavior.

Token Economy: Using tangible objects (ex: coins, stickers) as currency related to behavior.

Questions to Think About:

What are important behaviors that I think the plan should target?

How do I set up my child's environment at home to make problem behaviors less likely?

How do I respond to my child when they are misbehaving? What type of discipline works best?

Other questions you have:
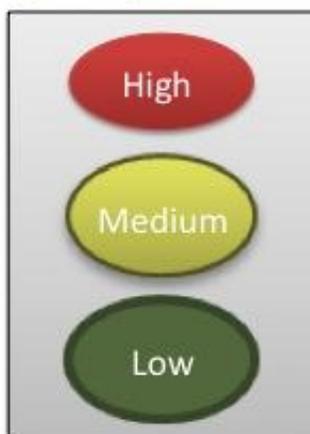
How concerned am I for this area?

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Behavior Intervention Plan

The Behavior Intervention Plan (BIP) outlines what adults and the child will do to increase positive (desired) behaviors and decrease negative behaviors.

People to Know:

School Social Worker: Provides services to support your child's behavior or emotions. S/he may meet with your child individually or in a small group to practice appropriate behavior, social skills, or emotional control. She may be a key person in writing and helping people at school to implement the plan.

Behavior Interventionist: May get involved if behaviors are complicated or extra challenging for the team and they want another person's expertise on working with kids with autism and their behavior.

School Psychologist: May help with data collection and designing the FBA and BIP.

Continuous Improvement Facilitator: Provides guidance and support to the team when students are having behavioral or academic concerns. This person typically has experience as a special education teacher.

Case Manager: The special education teacher or primary person who works with your child.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Counseling Services: The school social worker or school psychologist may work with the team to gather important information about the behavior. They also may provide services to support the child in carrying out the plan.

How concerned am I for this area?

High   **What information do I need to feel more comfortable?**

Medium   Who can I talk to?

Low   What do I want to say about this to my child's team?

Academic Performance

This section of the IEP describes the academic skills your child currently has and what is expected of a child in his/her grade.

Terms to Know:

MAP: (Measures of Academic Progress) Tests given in fall and spring to students to measure their math and reading skills

Checkpoints: Assessment given every 5 weeks to all students in the district to assess their progress on the State Standards

Fountas & Pinnell: A leveled reading program that follows student progress in reading

Decoding: How a child breaks down a word and reads the sounds in that word

Fluency: How quickly and accurately a child can read or calculate math problems

Comprehension: Understanding the important information in a reading passage

Kansas State Standards: Standards established by the state that outlines skills that students should be learning at each grade.

Extended Standards: Based on the State standards, these standards are modified for students with more significant needs.

Number sense: Understanding numbers, their relationships to each other, and how number operations work

1-1 correspondence: Understanding that 1 object or a group of objects represents a number, and vice versa

Writing mechanics: The rules of writing – like capitalizing, using punctuation, putting words in the right order.

Expressive: Being able to express yourself ands say what you know

Receptive: Being able to listen and understand terms when they are said to the child, so s/he can show what s/he knows

Whole word instruction: Learning to read by learning the whole word rather than the sounds in word.

Guided Reading: The teacher works with students in a small group practicing specific reading strategies.

Animated Alphabet: Alphabet letters paired with pictures and songs to help children learn their sounds

Questions to Think About:

What areas of academics am I concerned about for my child?

What do I see as my child's academic strengths?

What are we doing at home to encourage progress in reading, math and writing?

Other questions you have:
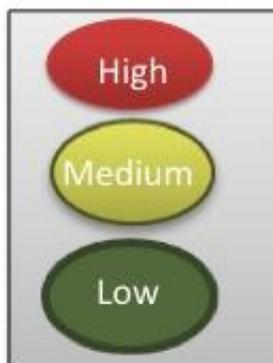
How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Academic Performance

Different people contribute to your child's education at school in different ways. Here are some people who may be talking with you about academics and describing how and where your child works on his/her academics.

People to Know:

Special Education Teacher: A teacher with specialized training in how to teach students with special learning needs. This person may also be called a case manager.

Case Manager: The special education teacher or primary person who works with your child.

General Education Teacher: There should be a classroom teacher or other teacher with experience working with the general population of students who knows the expectations for typical kids your child's age.

Para-professional: An adult who has training in supporting a special education teacher in his/her instruction for students with special needs.

Speech-Language Pathologist: Professional with specialized training in language development related to academics.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Special Education Services: These services support students in the ways that they need in order to progress academically and behaviorally.

Direct Services or Pull-Out Services: These are services provided outside of the general education classroom. They may take place in a variety of different types of settings (see Anticipated Services).

Collaborative Services: This is sometimes also called **inclusion,** and is a type of service where adults support a child within a general education classroom.

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Communication

This section of the IEP describes your child's language and communication skills.

Terms to Know:

Voice: Volume and tone of a child's voice

Fluency: A child's ability to produce natural sounding speech. In other words, does the child stutter?

Articulation: Motor production of speech sounds

Vocabulary: Words that represent things in our world

Picture Exchange Communication System (PECS): Child uses pictures to communicate and understand ideas, wants and needs when engaging with others.

Augmentative/alternative communication: A term used to describe multiple different ways of the use of a variety of tools to help children communicate.

Manding: Requesting an item (for example "Can I have a cookie")

Tacting: Labeling an item (i.e. when a child sees a cookie s/he says "cookie")

Intraverbal fill-in: Completing a sentence (ie A cow says _____)

"wh" questions:: Who, what, where, when, why questions

Receptive language: A child's ability to understand what others are saying

Expressive language: The language that a child produces

Intelligibility: How well a child's speech is understood by others

Final consonant deletion: Not producing the final consonants in words (ie "ca" for "cat"

Cluster reduction: Not producing all consonants in a consonant cluster (ie "sop" for "stop")

Pragmatics: The social use of language. For example, using eye contact, staying on topic during conversation, greeting others.

VB MAPP: (Verbal Behavior Milestones Assessment and Placement Program) a tool used to assess children's language and determine how to best address their language needs.

Questions to Think About:

How does my child currently communicate? (this might include using pictures, sign language, or behavior)

What would I like to see my child improve on with his/her communication?

Other questions you have:

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Communication

While the speech-language pathologist has the most expertise in communication/language skills and may write the communication goal, everyone who knows the child should be helping him/her develop his/her communication skills.

People to Know:

Speech-Language Pathologist: A professional specially trained in developing communication skills

Assistive Technology Team: Members of this team may provide recommendations regarding tools and other technology that can help your child with communicating.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Speech-Language Services: A professional with specialized training in language development and intervention.

Circle of Friends: A small group in which a child with autism or other social concerns practices appropriate play language, turn-taking behavior and social skills with 1 or 2 other typical peers. The group is led by a social worker and speech-language pathologist.

Communication Temptation Room: A classroom specially designed to encourage children to use language to communicate and interact with other people.

Assistive Technology: Technology tools to help facilitate communication.

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Life Experience/Self Help Skills

This section of the IEP describes your child's abilities to express wants and needs, and to take care of his/her personal needs.

Terms to Know:

Activities of Daily Living: Activities we do daily as part of our routine. These skills vary with age but could include getting dressed, using the bathroom independently, or making food.
Adaptive Skills: The specific skills needed to be able to accomplish the Activities of Daily Living. Also called self-help skills.
Personal Hygiene: Keeping clean and healthy. Includes bathing, cleaning self after using the bathroom, hand washing, teeth brushing.

Questions to Think About:

What self help skills does my child need to work on?

What are we working on at home that I would like my child to be practicing at school?

Other questions you have:

How concerned am I for this area?

High

What information do I need to feel more comfortable?

Medium

Who can I talk to?

Low

What do I want to say about this to my child's team?

Goals/Objectives

This section of the IEP outlines specific academic skills that are targeted for the next school year. These goals are flexible and can change based on your child's progress. For example, if s/he meets a goal early, it can be extended to the next skill s/he needs. If your child has difficulty meeting the goal, it can be broken down to address the specific skills s/he needs to reach their goal.

Terms to Know:

Goals: Specific skills that a child will develop. Skills could relate to academics, communication, behavior, or life skills. Should be able to be measured by an outside observer.

Objective: Measure of progress toward the annual goal

Benchmark: Milestones that describe skills to be learned, that can often be different skills combined together for a specific goal

Accuracy: Usually a percentage that shows how many a child got correct out of how many times they tried to do it.

Trials: The number of testing opportunities a child has to try and perform a skill.

Discrete Trial Instruction: The child is given a specific number of opportunities to perform a skill. The trials are presented the same way each time.

Questions to Think About:

What are the most important skills I want my child to learn in the next academic year?

What happens if my child meets a goal? What do I want them to be doing next?

How should we break down a goal if they are having difficulty reaching their benchmarks?

Other questions you have:

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Supplementary Aids and Services

This section of the IEP outlines any additional supports or services needed by a child in order to participate in school activities with other children without disabilities.

Terms to Know:

Supplementary: Aids, services, and other supports that are provided in regular education classes, other education-related settings, and extracurricular and nonacademic settings to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate. (based on Kansas Law K.A.R.91-40-1(ttt)) For example, assistive technology or paraprofessional services could be considered supplementary. Environmental supports might also fall in this area.

Visual Schedule: Schedule that outlines the activities of a child's day in pictures. For example, a picture of books represents reading, a swingset represents recess. The visual schedule may also show photographs of the child doing each daily activity.

Behavior Sheet: A sheet used to track behaviors the child may do throughout the day.

Questions to Think About:

What other types of supports does my child need in order to participate in school like other kids?

Other questions you have:

How concerned am I for this area?

High — **What information do I need to feel more comfortable?**

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Program Modifications and Accommodations

This section of the IEP outlines ways that academic materials need to be adjusted or changed in order to meet a child at his/her skill level.

Terms to Know:

Accommodation: Adapting a task or assignment to better fit a child's skill level. For example, reducing the number of math problems a child has to do in an assignment. Other accommodations might include:

Proximity to teacher: Being seated or working close to a teacher

Wait time: Giving a child time after asking them to do something or answer a question so that they can think about it

Visual Schedule: Schedule that outlines the activities of a child's day in pictures. For example, a picture of books represents reading, a swingset represents recess. The visual schedule may also show photographs of the child doing each daily activity.

Modification: Significantly changing a task or assignment to better fit a child's skill level. For example, changing the kind of math problem a child has to do for an assignment.

Questions to Think About:

How does my child need to have materials and information changed so that he/she can better understand it?

What's the best way for my child to show what he/she knows?

Other questions you have:

How concerned am I for this area?

High — **What information do I need to feel more comfortable?**

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Supports and Training for School Personnel

This section of the IEP outlines any training or support that is needed for people who work with your child. It might include training on a behavior plan or communication tools the child uses.

Terms to Know:

Supports: What other tools or guidance adults need in order to best work with a child. This might mean consultation from a special teacher or other professional.

Training: Skills that adults need in order to help the child make educational progress. For example, this might include training on an assistive technology device, sign language, or a software program the child will use.)

CPI: (Crisis Prevention Institute) Some school staff are trained in CPI techniques in order to be able to intervene safely when a student is behaving dangerously towards him/herself or someone else.

Questions to Think About:

Are there any special traits about my child or his/her needs that may be new to school staff and for which they would need special training?

Other questions you have:

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Assistive Technology Plan

This section of the IEP describes any technology or devices that your child may need to access or participate in his/her education. Terms listed below are just a sample of possible technology devices that may be available. Talk to your team for more details.

Terms to Know:

Assistive Technology: Any technology necessary to help a child participate and have access to his/her education.
Augmentative/Alternative Communication (AAC): A general name for a wide variety of tools used to help children communicate.
Picture Exchange Communication System: Using pictures to communicate about ideas, wants and needs.
Big Mac/Single Message Switch: Child is able to communicate by pressing a large button to play a pre-recorded message, up to 60 seconds long.
IPOD: A handheld device that can be used to play sounds or videos and can be equipped with applications to facilitate communication and other academic skills. Some of the applications used with the IPAD can also be used on an IPOD.
IPAD: A handheld touch-screen computer that can be used to help students with communication and other academic skills. There are several applications for the IPAD that are very helpful to students. One common app:
  Proloquo2Go: An application for the IPAD that helps with communication, by using pictures that can be touched to communicate words and create phrases.
Supertalker: Device with buttons that can be pushed to communicate up to 8 words. It can be programmed with pre-set vocabulary words to use during circle time, lunch, recess, etc.
ChatPC: Palm Pilot with a communication system on it. Very portable and easy to use.
Dynavox: Small computer used as a communication device as well as be programmed to manipulate the environment (for example, turn on lights or radio).

Questions to Think About:

Does my child need any technology or device to help with communication, completing academic tasks, or getting around the building?

Do I know what types of assistive technology might be available or useful?

Other questions you may have:

How concerned am I for this area?

High

What information do I need to feel more comfortable?

Medium

Who can I talk to?

Low

What do I want to say about this to my child's team?

Assistive Technology Plan

This section of the IEP describes any technology or devices that your child may need to access or participate in his/her education.

People to Know:

Speech-Language Pathologist: A professional specially trained in developing communication skills.

Occupational Therapist: A professional specially trained in the fine motor skills needed for a child to participate in their school work.

In KCKPS, either one of these types of professionals may be working with your child on assistive technology. It is typically a different person than the professional working on your child's communication or fine motor skill goals.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.
Assistive Technology Services: These services include assessment of skills and needs, and then providing students with some form of device or tool that they can use at school to help them to better participate in their educational activities.

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

State Assessments

This section of the IEP describes the type of assessment your child will take as part of the annual assessments taken by all students in Kansas in 3rd grade and older.

Terms to Know:

Kansas Computerized Assessment (KCA): Assessment taken on the computer by all students in grades 3-12 in Kansas. Assesses reading and math.

Kansas Assessment with Modified Measures: Similar to the KCA, still taken on the computer, but with fewer problems and shorter tasks to complete.

Kansas Alternate Assessment: A test, based on the Extended Standards, that is designed by a teacher to assess student progress on their IEP goals that tie to the Extended Standards.

Accommodations: Supports that need to be implemented for a student every time they are assessed. Common accommodations include having questions and answers read aloud, working on the assessment in a separate setting from classmates, taking breaks during the assessment, using a communication device to answer questions.

Questions to Think About:

How does my child learn and work best?

What should adults at school know about the ways we should adapt his/her testing environment to make sure we get the best representation of his/her skills?

Other questions you may have:

How concerned am I for this area?

High — **What information do I need to feel more comfortable?**

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Local and District Assessment Participation

This section of the IEP describes what accommodations may be needed by your child in order for him/her to participate in assessments given by the district and school.

Terms to Know:

Checkpoints: District assessments given to all students in all grades to assess their progress on State Academic Standards

MAP: Measures of Academic Progress. A national test that assesses student skill levels in reading and math. Given in the fall and spring of each school year.

Questions to Think About:

How are we measuring my child's progress using these district assessments?

What support does my child need in order to show what s/he knows best?

Other questions you may have:

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Special Education and Related Services

This section of the IEP outlines what kinds of special education services your child is receiving, how often s/he receives those services, and where the services are provided. If s/he needs a special program for his/her services, s/he will be bussed to a school with the services available.

Terms to Know:

STEPS: Structured Teaching for Educational Progress and Success. This program provides educational experiences for students with communication, sensory, and behavioral needs who may or may not have co-occurring cognitive delays. Currently, STEPS is available at Lindbergh, ME Pearson, and Silver City Elementaries.

Life Skills: A specialized program designed for children with cognitive delays, and/or other significant disabilities. The program focuses on developing life skills as well as academic abilities. Currently, Life Skill classrooms are found at Caruthers, Silver City, and Stony Point North Elementaries.

SLC: Student Learning Center. This setting provides resources and support for students with special needs. Every public elementary school in Kansas City, KS has Student Learning Center services.

Questions to Think About:

In what kind of setting will my child learn best?

Other questions you may have:

How concerned am I for this area?

High

Medium

Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Special Education and Related Services

People to Know:

Special Education Teacher/Case Manager: Oversees the specialized educational services your child receives and keeps track of all the important information about your child. S/he typically will set up any meetings you may have and would be the first person you should ask about any questions you have.

Speech-Language Pathologist: Specially trained in understanding and developing communication skills

School Social Worker: Provides services to support your child's behavior or emotions.

School Psychologist: Specially trained in assessment and intervention for children's needs.

Adaptive PE Teacher: A physical education teacher who has special training in adaptive physical activities to meet student sensory and physical needs

School Nurse: Trained to work in a school setting and address student health needs in a school setting.

Occupational Therapist: Works with the student on fine motor skills related to education.

Physical Therapist: Works with the student on gross motor skills important to his/her education.

Music Therapist: Uses music to assist students with disabilities to attain specified educational goals.

Services to Know:

*Students need to be found eligible before receiving these services. Talk to your team about possible eligibility.

Speech-Language Services: Develops students' skills in their ability to communicate

Counseling Services: Supports students' behavior and social emotional skills

Circle of Friends: A small group experience in which a child with autism participates with typical peers to practice communication and social skills. Facilitated by a social worker and speech-language pathologist.

Assistive Technology: Technology or other devices that help a student to better participate in the education

Adaptive PE: Specially designed instruction for children with special physical or sensory needs

Occupational Therapy: Services that provide students with sensory or fine motor skill support.

Physical Therapy: Services that provide students with gross motor skill development.

Communication Temptation: A specially designed room that encourages communication and language.

Special Education Services: Specially designed instruction for students with special needs

Music Therapy: Services that use music to help students develop academic skills and attain specific educational goals.

Vision Services: Services designed to help students who have visual impairments access and progress in the general curriculum.

Hearing Services: Services designed to help students who are deaf or who have hearing impairments access and progress in the general curriculum.

Transportation: Provided for students who need to access a specific program or who have special transportation needs.

How concerned am I for this area?
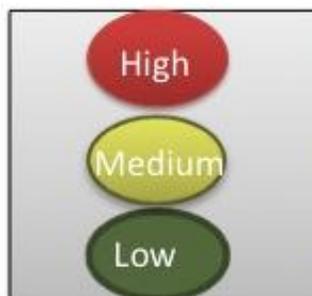
High
Medium
Low

What information do I need to feel more comfortable?

Who can I talk to?

What do I want to say about this to my child's team?

Anticipated Services

This section of the IEP outlines the types of services your child receives, as well as where, how much, and how often your child receives special education services in a chart format.

Terms to Know:

Service: The code for the type of service being provided. (Common codes are listed below
  SE: special education
  SS: speech language services
  OT: occupational therapy
  PT: physical therapy
  AS: assistive technology services
Setting: Where the service is provided (indicated by a G or C code from below)
  G: Services provided in a separate, special education setting. This may be individual (1 on 1) services, or services in a small group. But your child will be separated from general education peers.
  C: Services provided to the child in the general education setting
Attendance Building: The school where the student attends to receive services.
Provider: The name of the person who will see your child for the service.
Service Frequency: How often the service is provided.
Mins: How many minutes long the service lasts
Days: How many days per week your child will receive the service
Wks: The number of weeks your child will receive the service

Questions to Think About:

What types of services seem like they will address my child's needs?

Are there any services my child is not getting that I would like to have the team look at eligiblity for?

Are there any services my child is getting that I don't think s/he needs?

Other questions you may have:

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Extended School Term

The Special Education Department offers eligible students the opportunity to work on their IEP goals over the summer. Factors the IEP team considers when discussing eligiblity for Extended School Term are listed below.

Terms to Know:

Regression/Recoupment: If the team notices that a child has the tendency to regress over breaks, or has lost ground over time.

Degree and/or rate of progress: How much or how quickly a child makes progress toward his/her goals

Emerging skills/breakthrough opportunities: If the child is very close to making gains in skills

Interfering behaviors: Behaviors that may get in the way of the child making progress

The nature and/or severity of the disability: What kind of disability and how significantly it impacts their performance

Special circumstances or other factors: Other factors that are unique about this child

Questions to Think About:

Does my child seem to regress over breaks?

What will extended school term be like? Who will teach my child during that time?

Other questions you may have:

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Extent of Participation in General Education and Harmful Effects

This section reviews how much time your child has the opportunity to interact with his/her general education peers as well as the potential negative effects of receiving these services.

Terms to Know:

Harmful Effects: What are the negative effects that could result from implementing this IEP? (For example: A common harmful effect for a student in STEPS is that they will miss time with their general education peers while being in the STEPS classroom.)

Questions to Think About:

What are ways that we can ensure that my child is able to interact with typical peers?

What potential harmful side effects could be possible for my child by participating in special education?

Other questions you may have:

How concerned am I for this area?

High — What information do I need to feel more comfortable?

Medium — Who can I talk to?

Low — What do I want to say about this to my child's team?

Special Considerations

If there are is any other special information to consider, you will find it here. This may include special transportation or needing to access one of the special programs mentioned earlier (for example, STEPS).

Terms to Know:

Home/Neighborhood School: The school in your attendance area, closest to your home address

Special Transportation: A bus from the school district that will pick up your child from a specific location near your home and take him/her to the school that has the program s/he needs

Questions to Think About:

What are the advantages and disadvantages about receiving services at a school different from my child's neighborhood school?

Other questions you may have:

How concerned am I for this area?

High   What information do I need to feel more comfortable?

Medium   Who can I talk to?

Low   What do I want to say about this to my child's team?

Destruction of Records

The school district keeps special education records on every child with an IEP. They are required by law to tell you when they destroy those records.

Terms to Know:

Records are destroyed 5 years after a student leaves special education services.

Questions to Think About:

Do I need any copies of my child's special education records?

Who else may I want to share my child's special education records with?

Other questions you may have:

How concerned am I for this area?

High

What information do I need to feel more comfortable?

Medium

Who can I talk to?

Low

What do I want to say about this to my child's team?

Contact List for My Child's School

Job Title	Provider Name	Phone Number/Email

Glossary of People

Adaptive PE Teacher: A physical education teacher who has special training in adaptive physical activities to meet student sensory and physical needs in a small group environment

Assistive Technology Team: Members of this team may provide recommendations regarding tools and other technology that can help your child with communicating.

Behavior Interventionist: May get involved if behaviors are complicated or extra challenging for the team and they want another person's expertise on working with kids with autism and their behavior.

Case Manager: The special education teacher or primary person who works with your child.

Continuous Improvement Facilitator: Provides guidance and support to the team when students are having behavioral or academic concerns. This person typically has experience as a special education teacher.

General Education Teacher: There should be a classroom teacher or other teacher with experience working with the general population of students who knows the expectations for typical kids your child's age.

Occupational Therapist: Works with the student on fine motor skills and sensory needs related to education.

Para-professional: An adult who has training in supporting a special education teacher in his/her instruction for students with special needs.

Physical Therapist: Works with the student on gross motor skills important to his/her education.

School Nurse: A health care professional trained to work in a school setting and address student health needs in a school setting.

School Psychologist: Professional with special training in assessment and behavior. May help gather data about your child's behavior or provide counseling services.

School Social Worker: Provides services to support your child's behavior or emotions. S/he may meet with your child individually or in a small group in a special education classroom or general education classroom to practice appropriate behavior, social skills, or emotional control.

Special Education Teacher: A teacher with specialized training in how to teach students with special learning needs. This person may also be called a case manager.

Speech-Language Pathologist: Professional with specialized training in language development related to academics.

Glossary of Terms

Accommodation: Adapting a task or assignment to better fit a child's skill level. For example, reducing the number of math problems a child has to do in an assignment. Other accommodations might include:

   Proximity to teacher: Being seated or working close to a teacher

   Wait time: Giving a child time after asking them to do something or answer a question so that they can think about it

   Visual Schedule: Schedule that outlines the activities of a child's day in pictures. For example, a picture of books represents reading, a swingset represents recess. The visual schedule may also show photographs of the child doing each daily activity.

Accuracy: Usually a percentage that shows how many a child got correct out of how many times they tried to do it.

Activities of Daily Living: Activities we do daily as part of our routine. These skills vary with age but could include getting dressed, using the bathroom independently, or making food.

Adaptive PE: Adapt typical physical education to meet unique sensory or physical needs that students have, working in a small group setting.

Adaptive Skills: The specific skills needed to be able to accomplish the Activities of Daily Living. Also called self-help skills.

Animated Alphabet: Alphabet letters paired with pictures and songs to help children learn their sounds

Antecedents: Things that happen prior to the behavior that make it more or less likely to happen.

Articulation: Motor production of speech sounds

Assistive Technology: Any technology necessary to help a child participate and have access to his/her education.

Attendance Building: The school where the student attends to receive services.

Auditory: Hearing

Augmentative/alternative communication: A term used to describe multiple different ways of the use of a variety of tools to help children communicate.

Baseline: What the child is currently doing

Beery Motor Coordination: assessment that examines a child's ability to maintain fine motor control of the fingers when putting written work on paper (another subtest of the VMI)

Beery Visual Perception: assessment that examines a child's ability to perceive similarities and differences in objects and designs (a subtest of the VMI)

Beery VMI: assessment that examines a child's ability for hand-eye coordination. How they can look at and imitate various shapes and designs

Behavior Intervention Plan: A plan that describes ways to support a child to engage in appropriate behavior, and how adults need to respond if a child behaves inappropriately.

Behavior Sheet: A sheet used to track behaviors the child may do throughout the day.

Benchmark: Milestones that describe skills to be learned, that can often be different skills combined together for a specific goal

Big Mac/Single Message Switch: Child is able to communicate by pressing a large button to play a pre-recorded message, up to 60 seconds long.

ChatPC: Palm Pilot with a communication system on it. Very portable and easy to use.

Checkpoints: Assessment given every 5 weeks to all students in the district to assess their progress on the State Standards

Cluster reduction: Not producing all consonants in a consonant cluster (i.e. "sop" for "stop")

Comprehension: Understanding the important information in a reading passage

Consequences: Things that happen after the behavior that make it more or less likely to happen.

Control: Another student in the classroom being compared to the target student

CPI: (Crisis Prevention Institute) Some school staff are trained in CPI techniques in order to be able to intervene safely when a student is behaving dangerously towards him/herself or someone else.

Glossary of Terms

Data: Information about the behavior, which could include a count of the behavior, rating of the behavior, school records, or information from an interview

Duration: How long a behavior lasts

Days: How many days per week your child will receive the service

Degree and/or rate of progress: How much or how quickly a child makes progress toward his/her goals

Decoding: How a child breaks down a word and reads the sounds in that word

Discrete Trial Instruction: The child is given a specific number of opportunities to perform a skill. The trials are presented the same way each time.

Does the behavior impede learning of the child or others? This question asks whether a behavior or set of behaviors interferes with a child being able to learn.

Duration: How long a behavior lasts

Dynavox: Small computer used as a communication device as well as be programmed to manipulate the environment (for example, turn on lights or radio).

Emerging skills/breakthrough opportunities: If the child is very close to making gains in skills

Environmental Supports: How the environment will be designed to encourage appropriate behavior.

Expressive language: The language that a child produces

Extended Standards: Based on the State standards, these standards are modified for students with more significant needs.

Expressive: Being able to express yourself and say what you know

Final consonant deletion: Not producing the final consonants in words (i.e. "ca" for "cat")

Fine Motor: Small-scale motor skills, such as holding a pencil, cutting with scissors, using a fork and spoon.

Fluency: (academic) How quickly and accurately a child can read or calculate math problems

Fluency: (speech) A child's ability to produce natural sounding speech. In other words, does the child stutter?

Fountas & Pinnell: A leveled reading program that follows student progress in reading

Frequency: How often a behavior happens

Frequency Count: Keeping track of how many times a behavior occurred in a specific time period.

Function: Why the child does the behavior.

Functional Behavior Assessment: Collection of information about a behavior to determine why it's happening and how to improve the behavior.

Goals: Specific skills that a child will develop. Skills could relate to academics, communication, behavior, or life skills. Should be able to be measured by an outside observer.

Generalization: Being able to demonstrate behavior or social skills across a variety of settings.

Gross Motor: Large-scale motor skills, such as being able to run, walk, skip, jump, climb, and do the activities needed to get around the school building and participate in physical education and recess.

Guided Reading: The teacher works with students in a small group practicing specific reading strategies.

Harmful Effects: What are the negative effects that could result from implementing this IEP? (For example: A common harmful effect for a student in STEPS is that they will miss time with their general education peers while being in the STEPS classroom.)

Home/Neighborhood School: The school in your attendance area, closest to your home address

Intelligibility: How well a child's speech is understood by others

Intensity: How severe a behavior appears to be.

Interfering behaviors: Behaviors that may get in the way of the child making progress

Interview: Perspectives about the child's behavior from people who know the student.

Intraverbal fill-in: Completing a sentence (i.e. A cow says _____)

Glossary of Terms

IPAD: A handheld touch-screen computer that can be used to help students with communication and other academic skills. There are several applications for the IPAD that are very helpful to students. One common app:

   Proloquo2Go: An application for the IPAD that helps with communication, by using pictures that can be touched to communicate words and create phrases.

IPOD: A handheld device that can be used to play sounds or videos and can be equipped with applications to facilitate communication and other academic skills. Some of the applications used with the IPAD can also be used on an IPOD.

Kansas Alternate Assessment: A test, based on the Extended Standards, that is designed by a teacher to assess student progress on their IEP goals that tie to the Extended Standards.

Kansas Assessment with Modified Measures: Similar to the KCA, still taken on the computer, but with fewer problems and shorter tasks to complete.

Kansas Computerized Assessment (KCA): Assessment taken on the computer by all students in grades 3-12 in Kansas. Assesses reading and math.

Kansas State Standards: Standards established by the state that outlines skills that students should be learning at each grade.

Kinesthetic: Hands on, using the body

Manding: Requesting an item (for example "Can I have a cookie")

MAP: (Measures of Academic Progress) Tests given in fall and spring to students to measure their math and reading skills

Mins: How many minutes long the service lasts

Modality: Method of Learning

Modification: Significantly changing a task or assignment to better fit a child's skill level. For example, changing the kind of math problem a child has to do for an assignment.

Motivation Assessments: Tools used to determine what types of things might motivate a child's behavior. Common assessments used in KCKPS include the Motivation Assessment Survey or the Dunn-Rankin Reward Preference Inventory.

Number sense: Understanding numbers, their relationships to each other, and how number operations work

Nursing Plan/Health Care Plan: A plan that outlines services provided by a trained nurse.

Nursing Services: Health care services that can only be given by a medical professional. May include changing a medical apparatus (like a colostomy bag), or feeding students through a G tube.

Observation: When a neutral person watches what happens in a classroom, focusing on a specific child, comparing them to another child the same age and gender.

Objective: Measure of progress toward the annual goal

Occupational Therapy: Address a child's fine motor skill and sensory needs.

Peabody: assessment that examines young children's developing motor skills in a variety of areas.

Personal Hygiene: Keeping clean and healthy. Includes bathing, cleaning self after using the bathroom, hand washing, teeth brushing.

Physical: (prompt)Moving or otherwise guiding the child to do what you want them to do.

Physical Therapy: Address a child's gross motor skill needs.

Picture Exchange Communication System (PECS): Child uses pictures to communicate and understand ideas, wants and needs when engaging with others

Positive Behavior Supports: A system of intervention and prevention approaches to encourage appropriate behavior.

Glossary of Terms

Pragmatics: The social use of language. For example, using eye contact, staying on topic during conversation, greeting others.

Prompt: A direction to get started on an activity. Can be verbal, visual, or physical.

Provider: The name of the person who will see your child for the service.

Reactive Strategies: How adults respond to a child when he/she has inappropriate behavior.

Receptive: Being able to listen and understand terms when they are said to the child, so s/he can show what s/he knows

Receptive language: A child's ability to understand what others are saying

Redirection: Correcting a child and prompting them to engage in the appropriate behavior when they do otherwise.

Referral: Information about what behaviors are happening and why they are a concern.

Regression/Recoupment: If the team notices that a child has the tendency to regress over breaks, or has lost ground over time.

Reinforcement: Privileges, objects, or other events that encourage a behavior to happen more often.

Scatter plot: A graph that represents how often different behaviors happen over time.

Sensory Diet: Ideas or suggestions of various sensory input to add to a child's day or ways to avoid or work around input that is disturbing to a child in order to help them function better in their environment

Sensory input: information that is sent to our bodies from the 7 sensory systems (see sensory systems)

Sensory Profile: An assessment that examines a student's sensitivity to different sensory inputs like sounds, light, touch, and other sensations.

Sensory Seeking: A person that seeks out additional input through their day. They need to input to help them function better. (i.e. rocking, spinning in a chair, listening to certain music, tapping fingers, clicking a pen, etc)

Sensory Sensitive/Avoiding: A person who is sensitive to various sensory input or who goes out of their way to avoid input. It may disrupt their ability to fully function in their environment

Sensory systems: visual (eyes), tactile (touch), auditory (hearing), olfactory (smell), taste (mouth), vestibular (balance), proprioception (sense of where body is in space)

Sensory Threshold: The level of input that a person needs to function at their best. Someone with a high threshold needs more input to reach that level and someone with a low threshold needs less input.

Service: The code for the type of service being provided. (Common codes are listed below

   SE: special education

   SS: speech language services

   OT: occupational therapy

   PT: physical therapy

   AS: assistive technology services

Service Frequency: How often the service is provided.

Setting: Where the service is provided (indicated by a G or C code from below)

   G: Services provided in a separate, special education setting. This may be individual (1 on 1) services, or services in a small group. But your child will be separated from general education peers.

   C: Services provided to the child in the general education setting

Supertalker: Device with buttons that can be pushed to communicate up to 8 words. It can be programmed with pre-set vocabulary words to use during circle time, lunch, recess, etc.

Special circumstances or other factors: Other factors that are unique about this child

Special Transportation: A bus from the school district that will pick up your child from a specific location near your home and take him/her to the school that has the program s/he needs

Glossary of Terms

Supplementary: Aids, services, and other supports that are provided in regular education classes, other education-related settings, and extracurricular and nonacademic settings to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate. (based on Kansas Law K.A.R.91-40-1(ttt)) For example, assistive technology or paraprofessional services could be considered supplementary. Environmental supports might also fall in this area.

Supports: What other tools or guidance adults need in order to best work with a child. This might mean consultation from a special teacher or other professional.

Tacting: Labeling an item (i.e. when a child sees a cookie s/he says "cookie")

Target: The student who is the focus of the observation.

Target Behavior: The behavior that we want the child to change.

Testing Accommodations: Supports that need to be implemented for a student every time they are assessed. Common accommodations include having questions and answers read aloud, working on the assessment in a separate setting from classmates, taking breaks during the assessment, using a communication device to answer questions.

The nature and/or severity of the disability: What kind of disability and how significantly it impacts their performance

Time sample: Observer keeps track of very short intervals of time and the type of behavior that happens in each interval. A percentage of time spent on- and off-task can be calculated from this observation.

Token Economy: Using tangible objects (ex: coins, stickers) as currency related to behavior

Training: Skills that adults need in order to help the child make educational progress. For example, this might include training on an assistive technology device, sign language, or a software program the child will use.)

Trials: The number of testing opportunities a child has to try and perform a skill.

VB MAPP: (Verbal Behavior Milestones Assessment and Placement Program) a tool used to assess children's language and determine how to best address their language needs.

Verbal: Telling a child what you want them to do

Visual: Pointing or showing a child what you want them to do.

Visual Schedule: Schedule that outlines the activities of a child's day in pictures. For example, a picture of books represents reading, a swingset represents recess. The visual schedule may also show photographs of the child doing each daily activity.

Visual Supports: Visual cues that help a student with staying on task and maintaining appropriate behavior.

Voice: Volume and tone of a child's voice

Vocabulary: Words that represent things in our world

"Wh" questions: Who, what, where, when, why questions

Whole word instruction: Learning to read by learning the whole word rather than the sounds in word.

Wks: The number of weeks your child will receive the service

Writing mechanics: The rules of writing – like capitalizing, using punctuation, putting words in the right order.

1-1 correspondence: Understanding that 1 object or a group of objects represents a number, and vice versa

Glossary of Services

Adaptive PE: These services adapt typical physical education to meet unique sensory or physical needs that students have.

Assistive Technology: Technology or other devices that help a student to better participate in the education

Circle of Friends: A specially designed group where your child may work with other typical peer models to practice social skills and communication in a playful and fun small group environment.

Collaborative Services: This is sometimes also called **inclusion,** and is a type of service where adults support a child within a general education classroom.

Communication Temptation: A specially designed room that encourages communication and language.

Counseling Services: Support from a specially trained social worker on a regular basis to address social, emotional or behavioral needs of your child.

Direct Services or Pull-Out Services: These are services provided outside of the general education classroom. They may take place in a variety of different types of settings (see Anticipated Services).

Music Therapy: Services that use music to help students develop communication or other academic skills.

Nursing Services: These are health care services that can only be given by a medical professional. It may include changing a medical apparatus, or...

Occupational Therapy: These services address a child's fine motor skill or sensory needs.

Physical Therapy: These services address a child's gross motor skill needs.

Special Education Services: Specially designed instruction for students with special needs

Special Transportation: a bus from the school district that will pick up your child from a specific location and take him/her to the school that has the program s/he needs

Speech-Language Services: Develops students' skills in their ability to communicate

Glossary of Programs

There are a variety of special education programs available in the district that may be fit for your child with autism. Your child must be found eligible:

Life Skills: A specialized program designed for children with cognitive delays, and/or other significant disabilities. The program focuses on developing life skills as well as academic abilities. Currently, Life Skill classrooms are found at Caruthers and Stony Point North Elementaries.

STEPS: Structured Training and Educational Programming for Students. This program provides educational experiences for students with communication, sensory, and behavioral needs who may or may not have co-occurring cognitive delays. Currently, STEPS is available at ME Pearson, Silver City, and Lindbergh Elementaries.

SLC: Student Learning Center. This setting provides resources and support for students with special needs. Every public elementary school in Kansas City, KS has Student Learning Center services.

Appendix C:

Consent Form

The University of Kansas

School Psychology Program
Department of Psychology and Research in Education

The Department of Psychology and Research in Education (PRE) at the University of Kansas supports the practice of protection for human subjects participating in research. The following information is provided for you to decide whether you wish to participate in the present study.   You may refuse to sign this form and not participate in this study.   You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

PURPOSE OF THE STUDY
This study will investigate the decision-making processes of parents of elementary-aged children with autism in Kansas City, KS public schools. From information obtained from interviews with parents and school personnel, and in partnership with a sub-group of the original participant group, a model will be developed of decision-making processes,   as well as a prototype tool to aid in decision-making for parents of children with autism working with their IEP team.

PROCEDURES
You will be asked to participate in group interviews with 5-7 other adults, either other parents of elementary-aged children with autism (if you are a parent) or with other school professionals (if you are a professional educator or related service provider). In these groups, you will be asked to respond to questions regarding common decisions that parents of children with autism must make, the factors parents consider in those decisions, and the support that parents need to help them make decisions. You will be asked to participate in at least 2 meetings with the larger focus group, and perhaps 2-3 additional meetings to participate in the Advisory Board, which will guide this researcher in designing a tool to help parents of children make decisions about their child's special education needs with their IEP team. These meetings will occur over the next 6-8 months.

Group interview meetings will be audio- and video-recorded to help the researcher in analyzing the information that you share. At follow-up meetings, I will review summaries of the points that I noticed in your statements, and you will have the opportunity to clarify or dispute any of the findings. I will de-identify the transcripts that are developed from our interview audio-recordings, and will destroy the original audio and video files 2 years from the date of these focus groups. The de-identified transcripts will be kept indefinitely, to

help me with further research. Observation notes will also be collected during the interviews, but will also be de-identified.

RISKS
You may feel some stress or anxiety when asked to recall decisions that were difficult for you, or to reflect on support that would help you with future decisions.

BENEFITS
By participating in this study, you have the opportunity to advance research, knowledge, and practice about how to assist parents in making decisions with their school IEP teams, and will advance understanding of the unique decision-making experiences of parents of children with autism living in Kansas City, KS.

PAYMENT TO PARTICIPANTS
You will not be paid for participation in the study. Water and light snacks will be provided to you during focus group meetings.

PARTICIPANT CONFIDENTIALITY
Your name will not be associated in any publication or presentation with the information collected about you or with the research findings from this study.   Instead, the researcher(s) will use a study number or a pseudonym rather than your name. Your identifiable information will not be shared unless required by law or you give written permission.

Permission granted on this date to use and disclose your comments remains in effect indefinitely.   By signing this form you give permission for the use and disclosure of your comments for purposes of this study at any time in the future.

The audio recordings will be transcribed into the qualitative data analysis software program Atlas.ti. Video recordings will be used to supplement transcript analysis. Both audio and video recordings will be destroyed two years after focus groups, or upon completion of my dissertation defense, whichever comes later. Transcripts will be de-identified and used only for research purposes.

REFUSAL TO SIGN CONSENT AND AUTHORIZATION
You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas.   However, if you refuse to sign, you cannot participate in this study.

CANCELLING THIS CONSENT AND AUTHORIZATION
You may withdraw your consent to participate in this study at any time.   You also have the right to cancel your permission to use and disclose further information collected about you, in writing, at any time, by sending your written request to:

Jessica Oeth Schuttler, Ed.S.
Department of Psychology and Research in Education
6th Floor, Joseph R. Pearson Hall
1122 W. Campus Rd
Lawrence, KS 66045

If you cancel permission to use your information, the researchers will stop collecting additional information about you.   However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

QUESTIONS ABOUT PARTICIPATION
Questions about procedures should be directed to the researcher(s) listed at the end of this consent form.

Jessica Oeth Schuttler, Ed.S.   Steven Lee, Ph.D.
Department of Psychology and Research in Education   PRE Department
6th Floor, Joseph R. Pearson Hall   6th Floor, JRP Hall
1122 W. Campus Rd   1122 W. Campus Rd
Lawrence, KS 66045   Lawrence, KS 66045
515-230-3971   785-864-9701
jessoeth@ku.edu   swlee@ku.edu

Appendix D:

Approval Letter from Participating School District

Approval Letter from KU-Lawrence Human Subjects Committee

Kansas City, Kansas Public Schools
Education Center
4601 State Avenue, Suite 38   Kansas City, Ks   66102
(913) 627-4999   Fax: (913) 627-2530   www.kckps.org

November 1, 2010

Jessica Schuttler
6101 W. 57th St.
Shawnee Mission, KS   66202

Dear Ms. Schuttler,

Thank you for the opportunity to review your application to conduct research in the USD 500 schools.   Your materials are complete and in good order, and we are pleased to convey approval to begin your work.   I must add that approval at district level does not imply any obligation for participation by particular schools or individual staff members.

We would like to be advised of your progress by a note to this office each semester you are engaged in work in our schools.   At time of completion, we request that you file a written report of your findings with us.   In the event that any component of your study changes, timely updates will be appreciated.   Please let us know if we may facilitate your progress in any way.   Best wishes for successful completion of your project.

Regards,

Dan Wright, Ph.D., NCSP (ret.)
Director, Research & Evaluation

Unified District 500

KU RESEARCH & GRADUATE STUDIES
The University of Kansas

10/29/2010
HSCL #18970
Jessica Oeth Schuttler
6101 W. 57th St.
Mission, KS 66202

The Human Subjects Committee Lawrence Campus (HSCL) has received your response to its expedited review of your research project

18970   Oeth Schuttler/Lee (PRE) The Design of an IEP Decision Aid: A Tool for Diverse Parents of Children with Autism

and approved this project under the expedited procedure provided in 45 CFR 46.110 (f) (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.   As described, the project complies with all the requirements and policies established by the University for protection of human subjects in research.   Unless renewed, approval lapses one year after approval date.

The Office for Human Research Protections requires that your consent form must include the note of HSCL approval and expiration date, which has been entered on the consent form(s) sent back to you with this approval.

1. At designated intervals until the project is completed, a Project Status Report must be returned to the HSCL office.
2. Any significant change in the experimental procedure as described should be reviewed by this Committee prior to
    altering the project.
3. Notify HSCL about any new investigators not named in original application. Note that new investigators must take

the online tutorial at http://www.rcr.ku.edu/hscl/hsp_tutorial/000.shtml.
4. Any injury to a subject because of the research procedure must be reported to the Committee immediately.
5. When signed consent documents are required, the primary investigator must retain the signed consent documents
    for at least three years past completion of the research activity. If you use a signed consent form, provide a copy of
    the consent form to subjects at the time of consent.
6. If this is a funded project, keep a copy of this approval letter with your proposal/grant file.

Please inform HSCL when this project is terminated. You must also provide HSCL with an annual status report to maintain HSCL approval. Unless renewed, approval lapses one year after approval date. If your project receives funding which requests an annual update approval, you must request this from HSCL one month prior to the annual update. Thanks for your cooperation. If you have any questions, please contact me.

Sincerely,

Mary Denning
Coordinator
Human Subjects Committee Lawrence
cc: Steven Lee

Appendix E:

Correspondence from District Personnel (not Advisory Board Members) Informing

Decision Aid Content

Re: please help! From: Betsy Jones To: Schuttler, Jessica Date: Friday - July 1, 2011 7:44 PM

Several of the kids in KCK are using ipods and ipads with the Proloquo2Go app, which is a communication app. it is really easy to use and is similar to the pecs but it talks and has layers of communication. Many of the students start out in preschool using a pecs book or a supertalker, which is a simple device that has up to 8 selections and very easy to program. Once the students increase vocabulary then we have introduced the ipod or ipad depending on access, the ipad is bigger and easier for students to access the icons on the app.

The pecs of course is very user friendly in that everyone understands a picture. This system is very functional and easy for everyone to use Supertalker is also easy to use and adaptable to any situation There are levels that can be pre-programmed so you can have a template for circletime, art, lunch etc. It is quick and easy to program and very easy to engage the student in the activity that is going on and give them a voice so they can participate with there peers

Ipad and ipod this technology is amazing!! The students are very interested in the technology and it is easy to use. The app is similar to the pecs in that you can build sentences. There is a lot of vocabulary that is already pre-programmed into the app but you can also customize this app to the specific student. These devices are also wonderful because they do so much more than the communication piece, there are reading, science, math, social stories etc... the list goes on and on so the student can use it for a variety of things.

Big mac switches are a single message switch that is used a lot during circle time, or small group instruction. These give the student an opportunity to be part of the activity and to have a voice. they hold up to 60 seconds of speech, so they are wonderful for answering questions during calendar time or to answer simple questions. Many of our students take them home and we send a message home to the family about what the student did at school that day and then the parents will send a message back so the student can share during circle time the next morning.

ChatPC- this is a palm pilot with a communication system on it. Similar to the ipod touch in that it is very portable and easy to use, has many layers(almost to many) we had a high school student using one of these and he was sort of proficient with it.

Dynavox: This is a very high tech device, this is a small computer. This is a communication device that does a variety of things, it communicates, it can be an environmental control in that you can program it to turn on your lights, tv etc.. and it is a computer. hope this helps, let me know if you need anything else.

>>> Jessica Schuttler 06/29/11 10:12 AM >>> Thanks Betsy, this is a great list to start with!

I am focusing on students with autism, so would you say there are some of these items that are more likely to be used by kids with autism? Are there other common assistive tech devices that kids with autism in KCKPS are using? I am trying to compile a list of

commonly used assistive tech devices for kids with autism (I'm thinking there could be a lot of communication types of devices, as well as the visual calendars and schedules), and then explain in brief, parent-friendly terms what each of those devices helps a student to do. I already had PECS on my list, as well as the big mac and switch (but I'm not sure if I have the best definition of what those are).I hope this helps to clarify a little bit. I'm compiling this list to be a part of a larger guide to help parents of kids with autism understand and participate in their IEP. If there are other terms that you use commonly when discussing assistive tech with parents that you notice they have difficulty understanding, could you send that to me as well?

Thanks so much for your help!! Jessica

Jessica Oeth Schuttler, Ed.S. School Psychologist Kansas City, KS Public Schools jeschut@kckps.org 913-627-7164 voicemail 913-627-3153 M.E. Pearson Office Disability is a natural part of the human condition, and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

>>> Betsy Jones 06/28/11 4:46 PM >>> Hi Jessica, I have been out of town and haven't been checking email. Not sure where to start, we have a huge variety of things that are offered. We have PECS(picture exchange communication system) big macs or single message switch, visuals such as calendars and schedules. We have tech talks, portable notetakers, tango, ipads, dynavox, software such as voice recognition, word prediction software, software that will read the text for the student. I could go on.... let me know if you need any more information. Betsy

>>> Jessica Schuttler 06/20/11 12:40 PM >>> Hi Ladies,

I hope you are enjoying your summer! I was wondering if you could do me a favor. As part of my dissertation, I am creating a tool that parents of kids with autism in KCKPS can use to help them better understand their IEP and make decisions with their team. I was wondering if you could send me some common terms that are used when you talk about assistive technology in IEPs, especially communication devices that you recommend for kids with autism. If you can help me with this, I would very much appreciate it!! I am working on this project over the summer, so if you could send me a reply within a few days of receiving this message, it will help me complete this project in the next few weeks. I am hoping to present the tool in late June/early July to my professor at KU and in August or September to my dissertation committee.

Let me know what questions you have. Thanks in advance for your help! Jessica

Jessica Oeth Schuttler, Ed.S. School Psychologist Kansas City, KS Public Schools jeschut@kckps.org 913-627-7164 voicemail 913-627-3153 M.E. Pearson Office Disability is a natural part of the human condition, and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results

for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

Re: speech terms From: Kimberly Haake To: Jessica Schuttler Date: Friday - May 27, 2011 4:01 PM

Jess,

Yes I would love to help! I do not use terms like "manding" and "tacting" because they are not common terms that parents use or know, but I will go ahead and define them for you because I know other SLPs use them.

Manding: requesting an item (for example "can I have a cookie")

Tacting: labeling an item (i.e. when a child sees a cookie he/she says "cookie")

Intraverbal fill-in: completing a sentence (i.e. a cow says....)

"wh" questions: who, what, where, when, why questions

receptive language: a child's ability to understand what others are saying expressive language: the language that a child produces

intelligibility: how well a child's speech is understood by others

articulation: the actual motor production of speech sounds final

consonant deletion: not producing the final consonants in words (i.e. "ca" for "cat")

cluster reduction: not producing all consonant in a consonant cluster (i.e. "sop" for "stop")

fluency: a child's ability to produce natural sounding speech. In other words, does the child stutter?

pragmatics: the social use of language. For example, using eye contact, staying on topic during conversation, greeting others.

That's all I could think of off the top of my head. Are there any other terms you can think of that you would like for me to define?

Kim

Kimberly Haake Speech-Language Pathologist Lindbergh Elementary M.E. Pearson New Chelsea Elementary 913-627-5150

>>> Jessica Schuttler 5/27/2011 3:21 PM >>> Hi Kim,

I was wondering if you could help me with something. As part of my dissertation, I am working on a decision-making aid for parents of kids in KCKPS with autism. The idea is that the tool guides parents through the sections an IEP. The guide includes common terms that parents in our district might hear when working with their IEP team. I was wondering if you could help with the terms for the Communication section of the IEP. Could you send me a list of common terms that you use as part of your section of an IEP? I am thinking things like manding, tacting, etc? It would be incredibly helpful to me and to our parents in KCK!Thanks!! Jess

Jessica Oeth Schuttler, Ed.S. School Psychologist Kansas City, KS Public Schools jeschut@kckps.org 913-627-7164 voicemail 913-627-3153 M.E. Pearson Office Disability is a natural part of the human condition, and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring

equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities.

Laura Ziegler

Hey Jess! I don't even know if this will still be helpful to you, but I promised I would do it and I meant it...I just keep forgetting:(I have thought about it more times than I can count, but you know how the beginning of the school year sucks the life out of you:(Well here goes, this is simply off the top of my head, if you want/need more then let me know! I focused mostly on the sensory with a few other OT terms as well. Again, let me know if you need more of an emphasis on the other.

Common Assessments:

Sensory Profile: looks at how a child takes in sensory input and how they react to it
(There are various versions of this including the caregiver questionnaire, school companion, infant/toddler, and just the original sensory profile...they all work towards the same goal, but are for various age groups or for different people to fill out)

Beery VMI: looks at a child's ability for hand-eye coordination. How they can look at and imitate various shapes and designs

Beery Visual Perception: looks at a child's ability to perceive similarities and differences in objects and designs (a subtest of the VMI)

Beery Motor Coordination: looks at a child's ability to maintain fine motor control of the fingers when putting written work on paper (another subtest of the VMI)

Peabody: looks at young children's developing motor skills in a variety of areas. OTs generally focus on the grasping and visual motor areas.

Common Terms:

Sensory systems: visual (eyes), tactile (touch), auditory (hearing), olfactory (smell), taste (mouth), vestibular (balance), proprioception (sense of where body is in space)

sensory input: information that is sent to our bodies from the 7 above sensory systems

Sensory Diet: Ideas or suggestions of various sensory input to add to a child's day or ways to avoid or work around input that is disturbing to a child in order to help them function better in their environment

Sensory Seeking: A person that seeks out additional input through their day. They need to input to help them function better. (i.e. rocking, spinning in a chair, listening to certain music, tapping fingers, clicking a pen, etc)

Sensory Sensitive/Avoiding: A person who is sensitive to various sensory input or who goes out of their way to avoid input. It may disrupt their ability to fully function in their environment

Sensory Threshold: The level of input that a person needs to function at their best. Someone with a high threshold needs more input to reach that threshold vs. someone with a low threshold who needs less input.

Fine Motor: the precise movements of the fingers, hands and arms

Visual Motor: the ability to simultaneously combine both vision and fine motor movements...i.e. hand-eye coordination

Hope that helps...like I said, let me know if you need more!

Laura

Appendix F

Sample Coded Transcript:

Focus Group #1

1 Je: Do you need anything else to drink, or eat or anything?

2

3 Ta: I'm trying to say your name.

4

5 Ka: Ka

6

7 Je: And we'll all go around and say our names and everything...

8

9 Ka: You don't say it the way you read.

0

1 Ta: Oh, okay.

2

3 Ka: crazy.

4

5 JE: okay

6

7 (laughing)

8

9

0 Je: do you need another pen or something?

1

2 Ka: It's mine,it's just...

3

4 Je: OH, did I have your name spelled wrong?

5

6 Ka: No, you have right, but this is the way you say it.

7

8 Je: OH, so this is the way you say it? I like that. Like a phonetic spelling or something!

9

0 That's good.

1

2 Ta: I found the letter today.

3

4 Je: oh, really?

5

6 Ta: She had taken it out of her bookbag, and it was - I found it when I was putting away laundry, it
   was in her drawer.

7

8 Je: ohh!

9

0 Ta: I was like, what in the world? (laughter) I don't think she did it on purpose.

1

2 Je: well that's so funny that it...

3

4 Ta: CUz i looked in her drawer, i don't see a letter, maybe they forgot to give it to her.

5

6 Je: I wondered about that too, cuz I think some teachers were like, oh I didn't get your flyer, in the
   mail, that I sent to them.Well, I'm glad you guys are here. So, I'll just explain a little about why you
   guys are here tonight. The reason that I asked you all to come is because I'm interested in hearing
   about your experiences working with your child's IEP team. So, things that have gone well, things
   that haven't gone so well, things that the district, or professinals in general could be doing better,
   and how we can better work together as parents and people from schools. I will tell you that I
   don't have any kids of my own, and I am an employee of the school district, but also that some of

this research is helping me with, um, my dissertation, a study I'm doing through the University of Kansas.So I will be sharing these findings with people at KU, as well as with people from the district. Um, I can assure that anything you guys say tonight will remain her confidential. You guys will also be helping Abbey with a bit of a study she's doing; she's also a student at KU, so she's here helping us tonight. Just want to set up a few guidelines that will help our conversation go smoothly. We are recording our conversation tonight so if we can speak clearly, and speak one at a time, that will help us (background noise, Lorena is arriving.) I'll ask you guys speak up claerly, take turns if you can. I'll try to make sure that everyone gets the chance to speak, I may say, well, someone else needs the chance to speak on that. WE will talk about 4 major questions that I"ll show you on our flip chart her, and we'll have some follow-up questions after that, but really I just want to hear what you allhave to say. So this is the most that I'll be talking this evening. Abbey will be assisting us with taking notes on the computer and helping us keep track of time so that we all get out of here as we said we would, okay? Um, I'd like to just go around with a little opener, if you could tell us your name, and the name of your child or children, and how many years you've been working with the Kansas City, KS public schools with the special education process. Te you want to start us off?

7

8   Te: Te , and my son's name is Tr, and he attends L Elementary, this is his first year in the KCK school district. He's in the first grade, we transferred from the G school district. So, it's been probably 3 years doing this IEP thing. So...

9

0   Ta: My name's Ta D, and my daughter is A, she's a 5th grader at L, and we've been in the district for about 2 years, this is our 3 rd year, and um, but she's 11, so we've been doing it since she was about 3 or 4 years old.

1

2   L: Hello my name is L, my son is M, he goes to C Elementary, he's in second. And, I've been ever since he was 2 and a half, so been there for a little while, been there with the school district and helping me and everything, here in KCK.

3

4   N: My name is N, and my son is G, he is 7, he was in G, we transferred from G, well, actually, we transferred from Texas, from Tx to G, from G to KS, and um, it's been a roller coaster since I've been here in KS, and i think we are on the right path now. We've been doing his IEP since he was 12 months, so , you know, we've been doing this for a little while.

5

6   K: I'm K, my son is M, he goes ot S, and we are in teh district for 3 years, yeah, he started preschool at the Ed Center, he just moved to S for kindergarten.

7

8   Je: alright, well thank you guys all for being here and sharing, it sounds like we have a nice range of experience, we'll get to hear different things, different schools, and different things, so...okay, we'll go ahead and start, the first question we had for you guys tonight, is uh, what educational decisions do you find yourself making as part of your IEP meetings? And that could be, things you're thinking about

9

0   Te: Um, usually when I go to the IEP meeting, they've already got everything outlined, as far as educational stuff, they set the goals, and you know, the guidelines that you know the guidelines they're going to try to meet by the end of the quarter, so really, I don't feel like I ever have anything to say about the educational decisions.

1

2   Je: oK

3

4   Te: So that's my experience.

5

6   K: I feel the same way.

7

8 Je: Anybody have anything different?

9

0 Ta: It's pretty much the same, they already have the goals already laid out, usually, I go in um, if there's spomething that is already outlined in the IEP that I disagree with I'll say let's change it like this, or I make suggestions, I would maybe like to see her do this, and they kind of fit it in, so,

1

2 Je: Can you give me an example of a time when you...

3

4 Ta: Um, like, they, they're trying to work with her as far as her social skills, so I requested, like, if she could have a buddy student. She's in a regular ed classroom, and she's pulled out for support services, and so um, i requested that she maybe have a student who could kinda of hang out with her, as a buddy, to help her, incorporate her more into the regular ed routine, and also um, there were some ideas that they thought would help, and I totally disagreed so I was like, no, let's nix that. We're not doing it.   And so, but kinda, other than that, I usually go with what they've already outlined.

5

6 Je: So, sometimes you're kind of finding yourself making requests about things like, social skills, something you mentioned. Or, you're either like disagreeing.

7

8 Ta: Like, they wanted to do, as an example, last year, they wanted to do like a little chart board where it was like a little sticker board, like, now it's time to go to lunch, now it's time to go to...and I was like, no, she's way too advanced for that. And,we kinda bumped heads at the meeting. They kind of felt, the person who initiated it, I didn't really know who she was, and the classroom teacher was like, she maybe asked about that stuff, 2 maybe 3 times in a morning, which is not that different from other kids in the classroom, so she said, I don't feel like she needs it any more than any other student, and so I said, we're not doing that.

9

0 Je: Anybody else, any other thoughts about...

1

2 N: Well, it goes right back to the same idea as what Ta is saying. It's like, my son has the behavioral issues and instead of making it an IEP, like an individualized, personalized goal, it's like the IEP comes to you, it's already structured, based on their decisions, and um, when you have your own issues, like, the behavioral, I'm needing a specialist and come in and try to work that behavior and help me with that behavior. And they'll just change the word, like um, we're working on this particular behavior, and I'm like, No you're not, tell me the steps you are doing to work on that behavior, and it's not really in there, you know, the guidelines are not really there, and um, my personal opinoin is, I think this school district needs a behavioral analyst, and the district says, oh we do have a behavioral analyst, and when it comes down to it, it's not, she's not able to do, what needs to be do,

3

4 Lo: it's like, they're still learning how to, how do you say

5

6 Je: incorporate?

7

8 Lo: incorporate the..

9

0 N: right, like, she's able to help the whole group as a whole, but not my individual child's needs. You know what I'm trying to say? And they are alike in so many ways, but they aren't, you know, they are very different. And so, what I would like to see is, my IEP goal or my IEP team take that into consideration and let's really break down that goal or that behavior, and let's not make it what every child in there is doing. I really want it catered to G's needs.

1

2 Je: so, individualized?

3

4 N: Individualized. And knowing exactly what Individualized IEP means. (laughs)

individu..~
lack of ..~

5

6 Je: So when you're thinking about, kind of about the decisions you're finding yourself making about the goals or the objectives or like the placement, like things about services for your child, would you say, you know what else would you say, would you add to what we've talked about. What other things..

7

8 Te: I can tell you that the IEP thing is kind of confusing. I have a really hard time understanding. So a lot of the times I don't even know what really is going on actually. Um, cuz, they have all these different goals and what they're gonna meet, but at the same time I'm like, "I don't wanna go through this whole thing and read this!" And they don't go through it in detail per page, per page, I mean it's just kinda like, here it is, and this is you know what we're doing. I mean, you're in an IEP meeting for maybe 15, 20 minutes.

confusio..~ Why don'..~ confusio..~ confusio..
confusio..~
overwhel..~

confusio..~ lack of ..~ overwhel..~
lack of ..~

9

0 N: And if you look at it, I mean, if you bring your IEP and I bring mine, we're gonna have something similar to it.

lack of ..~

1

2 (agreement noises)

3

4 N: And that's what I'm saying, what is on that IEP, the goals that they have, it absolutely means nothing, like, my son, on his IEP, it says he will be able to touch his nose, touch his head, clap his hand, I said, what? That has nothing to do with getting him in a structured environment and trying to eliminate his behaviors, because my personal opinion, if we're able to decrease some of his behaviors, then he's able to learn a whole lot more. Am I making any sense?

lack of ..~

lack of ..~

type of ..~

5

6 Ta: I find myself a lot of times in a meeting, you know when they're saying, A will be able to complete so many tasks with so much percent accuracy, it's like, I can't, I'm just like, did she meet the goal? Are we seeing progress? And so it's kinda like, you're not really sure you know, where they are in comparison to you know other kids because, um. I guess my philosophy with autism is, you're trying to work to get them as close to normal as possible, but you know that there's some limitations, and so my goal was always, I want to get her as close to what the other 5th graders are doing as possible, that means if, if we can only pull her out of the classroom for 30 minutes as opposed to 60 minutes, now if she's in the other classroom and she's throwing a fit then obviously she can't be there, but if she's able to do it, let's let her, because I understand with autism, a lot of it is like, like you said, behavior, it's teaching them behavior, and it can be confusing sometimes in those meetings.

confusio..~
parent r..~

peer com..~
faith~

type of ..~

confusio..~

7

8 Je: So I hear you guys saying that behavior is important for you

9

0 N: It's a major issue, and it has not been addressed in the Wyandotte County.

lack of ..~

1

2 Ta: Yeah, yeah, that's a major difference that I see from the district we were in to where we are now. They were always plugging away at trying to find ideas to get her to a point where she could learn, becasue she had severe behavioral issues in the beginning. And they figured it out to where, what they used, they had to implement it like 15, 20 times a day and it got to the point where they were only having to do it once a day, and it was something that, she was actually hey, if I do what I need to do, you know, I'll get this, I'll get that, and she was starting to learn and I feel like she maybe took a step back when she came to the district because of that.

system c..~

persiste..~
persiste..~ persiste..~ child ch..~

ME - 12/..
ME - too..

3

4 (Wow)

5

6 Lo: On my IEPs, when they explain to me, yeah he can do this, he can do that. He can do his numbers, and my son has a real speech issue. In letting us know, you know what he wants, what he needs, but it's that typical things, Mom always knows what our child wants, what our child needs, you know. So, I explained to them, well yeah you tell me he can do this, he can do that. Show me. And, videotape. For the last 3 years, I have been asking them to videotape it. Let me see it. They give me all the items so you know I can try it, but you know he sits there and he giggles and he laughs, like "haha I'm not gonna do it for you Mom."

7

8 (background: yeah, that's right)

9

0 L: At school though, at school he does it all the time.

1

2 N: And that's one of the things, in ___, you know, he was still young, but they videotaped. He was in school 5 days a week, and they videotaped 4 days of just him. And when I had my IEP meeting, that's what I was looking at. I was looking at visual IEPs. I wasn't looking at a bunch of paper that didn't mean anything to me. And I know you have to have a paper trail, but, the progress being met was all audiotaped, audio and visual taped, and you could see the progress that was being made. And when I came here, at _____, they were just like, well I gotta see if we can get a videotape and we gotta see....OKay, I'm alright with that. Go ahead and see. (laughing)

3

4 (laughter)

5

6 Lo: My teachers agreed on the videotaping, they said they can't do it all day, just like when he's actually doing it you know.

7

8 N: 30 minutes a day. What's wrong with that? That's okay, that should be incorporated into his IEP. I know that that's a lot of steps, I know it is a lot, but autism is so complex, we need to do a little bit more than just taking a step back approach. Hire someone, hire me! I don't have a job! OKay, I will sit there and videotape these kids, you know just to see you know, where they're at, because you know, you can get other people, I can get her to look at it, and she can say, you know, this is what I've done, to help out with this behavior, or something.

9

0 Lo: Maybe we can recommend on our IEPs, you know, VIDEO IEPs.

1

2 N: I've got it in my IEP, but you know, the excuse that I get, you know, we just don't have the time, or, we don't have anybody that can do that.

3

4 Lo: I think if you read in your parent rights, we do have the right, to you know step up and say you know you guys aren't doing your job, we want it done this way.

5

6 N: mmhmm

7

8 Je: K, how about you? You're staying quiet on this. What kind of decisions are you finding yourself making? Are your experiences similar or different?

9

0 K: Mine are the same, except I don't have the behavioral problem with my son.Yeah, I don't have at all.

1

2 Ta: You're lucky.

3

4 Others (yeah...)

5

6 K: But on the other hand, he's 5 years old, but his brain, is you know 18 months, you know, baby

brain. And then, I really prefer to have the behavior problem that he can go...Like because one day, deciding things in the IEP, like, in the transitional IEP, they were like, he gotta go to the doctor, they need to give him medicine for ADD. And I was saying, how can you tell my son needs the ADD medicine, if his brain is 18 month brain? He cannot do the things that a 3 yr old, or 5 year old, we need to look at him as a baby, his brain is baby, his body is not a baby body, but his mind is. We did have a big problem with that. He's now on the ADD medicine, because it helps him focus a little more. But he's still not learning the way he's supposed to learn.

7

8 Je: So I'm hearing you guys tell me a lot about what's making it challenging to make these decisions. Can you tell me anything about what makes it easier to make a decision? What, if anything, or anybody has helped you?

9

0 (Group sigh)

1

2 Te: Um, I don't know, I don't feel, being changed from the [previous] school district, we were just talking about this. I feel like, the teacher at the [previous] school district was a big advocate for my son. I mean, she just knew him, she knew how to get him straightened out, and just was a big, big advocate. So I think a lot of it has to do with how much the teachers really care about your child and how concerned they are about them achieving and succeeding. So I think that's a big help. Since I've only been in this school district a very short time, I haven't had that experience yet. But...

3

4 N: You have to have a teacher that cares, that's passionate, and has had some dealing with autism. It's one thing to have some dealing with special education, that's one thing, but autism is different than just a learning disability. You know, it's a spectrum. And you have to have a teacher that understands the spectrum and how to apply certain changes. And, that's what I was explaining to her, with Ms. A. Ms. A was the type of teacher, she was great. She was very sweet. That was her problem. She was a "sweet" teacher. This teacher I have now, she's not so "sweet." She makes G, G gets in there and gets to be bouncing around like a little bird, she'll tell him, we will not have birds today. Sit down. And that's what they need. I mean, that little sweet, timid voice, now G, I mean, that's what Ms. A was doing and G's still jumping and bouncing in her hands, you know. Don't cut no punches with G, you know. Make him sit down. And the authority in Ms. K's voice, he knows, okay, I'm gonna have to stop this stimming, Ms. K is not playing that today. I'm going to have to sit down, I'm going to have to get my work done. You know. And since he's been here, he doesn't have to go time out. Well, she doesn't call it time out here, but he doesn't have to go there. He's learning, you know. It's the teacher. You know, they have to be strong teachers when you're dealing with autism.

5

6 Je: Would you say that carries over into the meeting that you're having with teachers, too? Like, if you know they're a certain way with your child, do you notice that also in a meeting with them? When you're thinking about your work together as partners? What do you guys think?

7

8 Te: I've only had one IEP meeting, since my son started school. So, I really can't answer that.

9

0 Je: Or even if you're talking outside of IEP meetings.

1

2 Te: I mean, like I had to talk to her yesterday, because I kept getting notes about his behavior. And that, to me, was a change, because he wasn't having that trouble in [previous school district]. And so, I'm concerned you know, and I was concerned because they were moving him over to 1st grade but I thought they were moving too fast. They were sending a lot of homework home. He's in first grade, and I thought the homework was too hard. So, it's a lot of different concerns, but um, we did talk, and I don't know, we'll just have to see how it goes, over the rest of the year. But, um, that's been my experience (chuckles).

3

4   N: Ms. K talks to me once a week. She's making contact with me and letting me know once a week. I was there with the whole behavioral issues. I mean, she let me know what the behaviors was, she tracked them, and she sent what she tracked home. So there wasn't this little, I call it, a negative note, sent home telling me "your son's doing this, your son's doing that" you know, I didn't want to hear that, you know! She sent me this, she calls it a data sheet, and her data sheet she's tracking, and I can see where the behaviors are decreasing. And it's such, it's comforting to me. And yeah, um, I do believe that, it has to be the teacher, the support of the teacher. She's not only supporting G, but she's supporting me as well. You know, so...she's just, she's different.

5

6   Je: I'm seeing lots of nodding heads...you guys--

7

8   Ta: Yeah, uh, my uh, my daughter she goes to a resource room and I stay in contact with the resource teacher. I talk to her probably more than the regular ed teacher. And she never has a problem calling me, and um, we used to do a thing, where um, they used to keep a notebook, and basically they would write every day, you know, this is what she did. And we don't do that now. She's able to go to school and not have as many behavioral issues. And so if anything arises and its out of the ordinary, she will call me and say "Mrs. D, A was doing this today" and it's not anything negative, like you know, like she was saying, she's just letting me know. And I'll tell her okay, well we're going to work on that, and so, I totally agree the relationship with the teacher is what really makes it easy. Because if you feel like you can talk to them, and you feel like they're advocating then the whole relationship's going to flourish.

9

0   (mmhmmms from the group)

1

2   Je: How about you, L? Is it the same for you? Are there teachers, other people who have helped you make decisions?

3

4   L: The teachers have helped me a lot with my son. He really don't have a behavior issue, his is just basically on speech. You can't get his speech. He understands a lot, he can follow directions. It's just his speech, trying to push it out there. And I just keep thinking to myself, what if I change him to another school? You know, to see if he might do better. And I just keep thinking, should I change him should I change him? And I just don't know what to do, because they say that transitioning could be a big issue, you know on the kids, when they move.

5

6   N: And it can also be very exciting for them.

7

8   Je: and when you say change schools, do you mean change him to a different kind of classroom or to a different building?

9

0   L: A different building. 'Cause he's at C Elementary, and the two other schools that they said, 'cause he's in a [center-based], class and I think the other schools are S and L? So I wasn't sure, you know, to evaluate how they work, and stuff like that. I mean, other - they have helped me where he's at now. 'Cause my husband's like, well, he's doing good. And I'm like, ahh, I just don't know what to do.

1

2   Je: Can you tell me more about what information you were trying to get to help you make that decision? You talked about going and visiting to "evaluate" for yourself?

3

4   Lo: Well, for the IEP I was also going in and talking to the teachers there on his speech, you know, she wasn't able to show up, and I was told that I could call her and ask her but then they had also explained to me you know what they're doing, what they're working on. 'Cause you know, when he was little they started off with the picture PECS, you know, with the little black and white pictures, the little color pictures, it wasn't happening. You know, like, he wasn't dealing with that. So, the

only ones, are his favorites. Those were the only ones he was using, like pictures of food. (group laughs) Pictures of food, and pictures of movies he wanted to watch. Those were the only ones. He had discriminated everything else, like, (taps table) that's what I really want. So...yeah, we've, they've tried many things on speech. They're supposed to be working on a computer machine, you know, to help get it out there, so I'm hoping, hoping something works. But, yeah.

5

6 Je: What about anybody else? What kinds of information - I heard you guys kinda say, you want to have something in your hands, that you can see, like a graph, or a video. You want someone who's maybe a little more specialized to be talking with you about this, to be sharing information. Maybe someone who's more specialized in speech, too, in communication.

7 Any other people you're talking to, besides teachers and related service providers who are helping you? Making decisions?

8

9 Ta: Like in the district?

0

1 Je: Like, anybody, like some people say family members, other people have other friends.

2

3 N: I talk to a lot of other mothers. I have talked to a TON of other mothers. And they have been the most helpful to me, with decision making. For a lot of my educational needs. But, [this school district] is like, you don't know who is who. I've never seen, I think I've seen her a couple of times. I've never seen half the mothers in this room, we don't have a strong Wyandotte County Autism Society, Yeah. And I think that's a major downfall. Because I think the more we stick together the more services we can get for our children.

4

5 Je: You guys are all nodding your head. Are you all in agreement with that too? Are you feeling the same? Anybody had anything different?

6

7 Ta: I have, just, I have a, my child, since she was 4 years old she has been meeting with a child psychiatrist, and um, she's not on medication now, but has been since she's been in school basically. And so I always go to him with, what is something they could be doing, and he, uh, not in this district but in the other district, would talk with her resource teacher and they would kinda communicate. And he would say, well tell them they need to do this, or ask them about doing this, or and a lot of it helped. You know, we found ways to implement his suggestions into her curriculum, and so that's one of the things, but, now, I don't really know of any support groups or anything. I'm always on the internet looking like...

8

9 N: It's all in Olathe, or Lee's Summit!

0

1 Ta: Yeah, like, autism works or whatever that is, (JE: Autism speaks?) Yeah, whatever that is, and I'm to the point now, where I need to talk with a parent with a teenager or preteen with autism, 'cause I'm like, I have other issues in my mind that I'm thinking about like going into puberty, and you know, it's like, I don't really know anybody I can talk to about that.

2

3 Je: okay, okay.

4

5 Lo: Better support groups in the district.

6

7 Je: I don't know if you can even read this, but I put, we need a network, umm I've got something, parent support, parents of older kids, just trying to get some thoughts. Abbey's got a much better outline there. I'm hearing a lot of what you're saying is taking us into the next question. The next question that Abbey and I have for you is kind of an overlap with the question we just talked about but, kind of thinking about how, different factors in your life, different aspects of your life may be playing a part in your decisions.

8

9 Te: I know that when I decided to move over here, uh, the very first thing I did before I even decided to move was to call the school district and find out how the special education program was over here. Because my son is just used to being in a class with 4 children, and that was my concern is that I didn't want him to be thrown into a class where there was like 15 children, and stuff like that. When I called, it was pretty much the same setting, so I thought, well, this is going to be okay.

0

1 N:The same, my son is in a class of 5, 6 kids, as well.

2

3 Je: So you guys were interested in what kind of programs, classroom, class size.

4

5 Lo: I've also been hearing, like, there's also classes for like, autistic kids. And I keep hearing, I'm like, where's this at? LIke, S, do they have a classroom for autistic kids?

6

7 Ka:No, no.

8

9 Ta: I was told L was the school that like specialized in autistic kids, and that was a factor in my decision to go to L. And, um, I guess the fortunate thing is that she really didn't need to be in, the kids were more severe. And I thought, like, well, the school is a smaller school, and she may not be in that actual autistic classroom, they have teachers there that, if she starts to go into one of her moments, you know, somebody can say, well, I know what's wrong with her, they're not going to be yelling or putting her in time out or something, because somebody there is going to have experience with autistic kids you know, to say, okay, she's exhibiting a behavior, and this is um...so, that was a big factor in choosing L was, was their expertise, I guess.

0

1 N: L, is um...when I moved from Texas.

2

3 Te: What part of Texas did you move from?

4

5 N: B---, Tx.

6

7 Te: Where's that by?

8

9 N: Ft. W.

0

1 Te: Okay, cuz I was, I'm originally from Texas, but I was probably deciding to move to Texas, and it seemed like they really had a good special education program. I mean, she even told me, if you want to, before you move down, if you want to come down just to see, you're more than welcome to. So, I had a really good feeling about that, so (laughs) it hasn't moved that way yet.But...

2

3 N: Well, you and I can talk later.

4

5 J: And I can clarify a little bit about the classrooms. There's kind of an autism classroom, its called STEPS, which stands for Structured Training and Education Program, with is kind of a focus on kids who have more autism spectrum-like behaviors. You don't have to have autism to be in the STEPS classroom, but a lot of kids who are in STEPS have autism, and LIfe Skills...

6

7 L: They never broke it down for me, so I never could understand...

8

9 N: That's another thing, when you're going in to...I guess, they never broke down the whole organization to me. When I came to L, you know, he was just thrown into STEPS I's class. Nor did G know what to expect. I was looking for someone, like a tour guide, like I'm looking, I need to know

what's going on.

0

1   L: it's like, they just read the information that the teachers had, and it's just like, we'll go here...

2

3   N: What does it mean? Right, well let's just put him over here. OK, but he's gonna be over there, but what does that really mean, what class is he really getting? What are they going to be working on? And, you know, he has a para from [other school district], is he going to get a para. And they're like, no, he's not going to get his own para. And I was like, oh, really?

4

5   Ta: That was something I didn't like. 'Cause A had, she had a para. I feel like there was just a lot more support in her other school. And maybe they don't have the resources, or the money. 'Cause like, we were in [other school district], and we moved to [other school district], and the principal was like, we're going to hire another teacher to work specifically with her. And I thought that was great. But, um, like here, and even like now, I'm always asking, what's going to happen when she gets to middle school? I know they have Life Skills, but you know, is she, what's the - I don't even know what ot expect moving into next year. And I'm always asking the same thing, you know, like what kinds of programs do they have for autistic kids once they get to middle school? Is it, you know, at some point, she needs to learn how to count money, tell time, be a productive citizen to the best of her ability, and are we going with that, versus you know, are we trying to see if she can go to a junior college? I mean, you know, you're just kinda seeing where she's at, and what happens next.

6

7   Je: So I hear you talking about short term things, like what kind of things is she going to be a part, like, going forward,

8

9   Ta: right.

0

1   Je: But I also hear you thinking about long term things, like where's she gonna be in college, what, are you guys kinda on the same page with that?

2

3   N: Well, her baby's older than my baby is, yeah, so...

4

5   Te: And my son is 7, so I am, in a way, well, I wonder what he's going to be like when he's 10, like I wonder if I'm going to have to still be helping him get dressed. Because, he can't do that now, I mean, I have to literally walk him through each step, or do it for him

6

7   K: change diapers...

8

9   Te: Um, so, those are the concerns

0

1   Ta: And with autism, that's the challenge, the kids are so different. I mean you can't have two kids that are the same. It's kinda like, I've kinda worked through some of the issues that maybe you all are dealing with, 'cause she's older, but...

2

3   N: I will trade you...(laughs)

4

5   Ta: But it's like, you know, you're just kind of wondering, you know, where do we go from here, and it's kinda fearful, when you think about the future you're not really sure...

6

7   N: And see, if we had that community, becaues I know a parent that has a 15-year-old daughter that you can definitely talk to. But if we had that autism community, where the parents can get together and we can discuss some of these things, you know. They have that in Texas! They had it at the school!

                                                                                            267

8

9   Te: Wow!!

0

1   L: Well maybe right here we can start something.   advocate..~
                                                                        support ..~
2

3   Te: I went to the autism support group in L S and did not find it to be helpful at all. Because it was   perspect..~   perspect..~
    based on education and IEPs and my son was just starting school, and so, and they were saying
    really bad stuff but I didn't experience that at all with that school district, with [previous] school   professi..~
    district. Not at all. My son went from not talking to being able to communicate everything (N: they   success ..~
    got my son to talk! That's right!), I mean, it was a tremendous change.   system c..~

4

5   Ta:I think that's maybe like, my daughter, she has a diagnosis, but sometimes I feel like, you know,   child ch..~
    it's not, like, she went from not talking to like…if you looked at her she looks like a normal kid, but
    if you were talking to her, and she says something off the wall, and you're like, okay, something's
    wrong with her. (laughter) Yeah, it's like, you know (N: like, what are you talking about??) Stuff that   child ch..~
    a lot of people might think in their mind, she says it out loud! (laughing). And so it's like, okay,
    she's not, you know. And it's kinda like, you know, I'm the only parent, I feel like I'm in it by myself.   lack of ..~
    I'm like, Am I the only parent in Wyandotte County? Cause, she can do what all the other kids can
    do, but she just, kinda, you know, are a little different, and so that's kinda, what you know, what I   peer com..~
    deal with all the time.

6

7   Te: I know when I tell people about my son, you know, even family members, who haven't seen   child ch..~
    him in a while, I'm like, you know he's autistic. And they're like "where?" and I say just sit back and   perspect..~
    watch him for a little while.

8

9   Ta: Exactly and it's like you don't want to tell people, but you feel like you need to because they're   assertin..~
    so unpredictable. It's like,   child ch..~
                                                                                                            parent k..~
0   perspect..~
1   Je: disclosure or something…   uncertai..~
2

3   Ta: Like, yeah, I need to tell you 'cause she may say something crazy and I don't want you to get   child ch..~
    offended! (laughing)   type of ..~

4

5   N: I just play it off. (laughs) I'm to the point where I'm just done explaining and you know, we'll be   child ch..~
    at WalMart, and this lady will be like, "ma'am" and I'm just like, "I know!"   parent r..~
                                                                                                            perspect..~
6

7   L: Most of the time, like, when we're out in public, and people will come up to him and say like "hi,   child ch..~
    how are you doing" and he'll just laugh or giggle, and they'll be like "oh, he's shy". I say, yeah, he's   consider..~
    shy, we're just in and out, and just go on with the flow. And some people try to hi-five or how you   parent r..~
    doing hand shake, and its like, you know, he's autistic, and I let them know.   perspect..~

8

9   N: I used to have little business cards, that I used to just pass out, but, I got tired of making the   parent r..~   parent r..~
    business cards (laughter).   perspect..~   perspect..~

0

1   Ta: Did you really?

2

3   Te: That's a good idea.

4

5   N: I just got exhausted with it, and you gotta make sure you pack them.

6

7   Te: Or wear on a shirt, (laughs)

8

9   Je: What were you putting on the business cards?

0
1   N: Hi, my son has autism, and if his behavior is inappropriate, this is the reasons why. And I gave   advocate..~   has own ..~
    the Autism Speaks, www.autismspeaks so that they can read about it.   assertin..~
                                                                                                            communic..~
2
3   Te: That's a great idea.
4
5   L: Yeah, to get people out...
6
7   N: Nooo, NOOO!
8
9   L: No?
0
1   N: You will be finding yourself looking for those cards before you go out, and you know, you'll put   Frustrat..~
    them right there by the door, you know, and then, somebody'll come up (G), take 'em, and it   overwhel..~
    even put them in the toilet one time, flushed them just to see, and then you're scared to go out,
    just because you don't have your cards. And no, I said no, forget it, I'm not about to handicap
    myself like that. You just come on, and if they get to asking, about why you're slapping yourself
    upside the eye, just say, I know.
2
3   L: I thought about doing something like that, for like, Halloween. I mean, my son, he likes to go   child ch..~   perspect..~
    out and do Halloween things. And people will say, like, why don't you say something for Trick or   consider..~
    Treat? And you know, it's like.   identify..~
                                                                                                            peer com..~
4
5   N: G was a ceiling fan baby. He was knocking on the door, like, "Trick or treat, smell my feet, let me   child ch..~
    see your ceiling fan."
6
7   (laughter)
8
9   N: I'm like, Oh, my god, and this man was like, Oh yeah, we got two children with autism.   consider..~
                                                                                                            perspect..~
0
1   Ta: I mean, that's the thing, you're like, your kid is interesting. And they are like...   child ch..~
                                                                                                            perspect..~
2
3   N: Girl. G is like, G is at the age now, where he wants to be Michael Jackson. Like, you can say, G,   child ch..~
    come here, and he won't come. But if you say Michael Jackson, he's like, "what."
4
5   Ta: My daughter has been advocating for her name to be changed for the past...   child ch..~   child ch..~
                                                                                                            communic..~
6
7   N: You should change it.   identify..~
8
9   Ta: Yeah.
0
1   N: Change it!
2
3   Ta: And she even tells people, my name is not A, my name is whatever it is this week.
4
5   N: Change it and see what she does.
6
7   Je: Just to kind of bring it back a little bit. To talk about some of the things you're thinking about. I
    hear you guys saying a lot about knowing the individual things about, G, you know, anybody. You
    know, kinda understanding their different characteristics. How about, you know, sometimes
    parents say, you know, their values, their personal belief systems impacts how they make
    decisions. Do you guys, does that play a role for you? I mean, its okay to say it doesn't. Or, maybe
    it does.

8

9 Ta: Like, ?

0

1 Je: Like, a values system or a belief system. For some people that's a religious faith, for other
people its just a sense of what's right. I don't know if that's something that's played a role for you,
for some other parents it has, but that might not be the case for you guys, I don't know.

2

3 N: Autism is such a shocker you don't have time to think about that kind of stuff.

4

5 L: Mmmhmmm.

6

7 Ta: My family, we're religious, but, I really can't say that it has, um, I think maybe um, maybe, I
mean I can't say that I've never decided not to do something because of my faith or to do
something when it specifically comes to, her education and stuff like that. I mean, I trust in God,
and I believe that he made her the way that she is for a reason. And that's something that I had to
deal with in the beginning. It was hard for me to accept that diagnosis. I'm always looking for,
ways to improve, you know, I'm always asking myself am I doing everything that I could be doing,
but at the same time, I'm not going to kill myself or wear myself out, I'm just going to be the best
mom I can be and know that as long as I'm taking care of her. I know that as long as I'm living my
life according to my beliefs I know that I'm doing everything right by her. You know, she's here for
a reason. And, it could very well be to teach me some things about myself.

8

9 N: Wow.

0

1 Ta: And so that's kind of how I've always looked at her and the diagnosis and everything.

2

3 N: That is awesome, girl.

4

5 Je: Anybody else want to share, K, do you have anything to add? (47:32)

6

7 K: I don't know, yeah, I think the same way. LIke, when I realize my son had anything, he was six
months old. And, the doctors, they never wanted to do anything, because my daughter, she's
seven, and she was in front of every other kid, everything she did was like before everybody. She
walked at 7 months, she talked, and we talk in Portuguese at home, and she talked like at 18
months, and the doctor said, "You compare him to her, because she's in front of everything." And I
said "No, I'm not comparing him to her, I'm comparing him to the other kids, at his age, and he's
not doing it" And the doctor said "Well, he's lazy, wait a little bit" and I started to realize, there is
something wrong with him. I saw him looking at me, and not looking at me, look kinda through
me. And I talked to my husband, and I said, you know, I think he's autistic, when I think he was, 12
months when I said that. And my husband, he had his brother, just passed away in June, and he
was 49, and he did have mental retardation. And my husband say like, I am not prepared, to have
another kid in my life, to take care like that. And I said, you know what, if God gave it to us, it is
what we got. And I love him, and he's a gift. And his name, in English, M---, it means gift of the
Lord. And I say, I gave him the name, and he is, a gift of the Lord! (others nodding, mmhmm in
agreement). And if I'm here to help somebody else, if I'm here to help him, or if he's here to help
me or to help somebody else, I am prepared. Because if it's what God wanted me to do, it's what
I'm going to do. And, I think we're doing good. Now, I think my husband accepts a lot more.
Because, at the beginning it really was hard for him, because of his brother. But, we've been seeing
M doing a lot better, because his brother was a 6 month baby brain. Four months ago, he died
with a 6 month baby brain, and he was 49 years old. And, uh, M is 18 months, and it is a lot better
than him. And what we wish, is if he keeps not growing the way he grows, but at least, he will be
able to change the diapers, dress himself, eating properly, going to the restroom and sit nicely,
don't go and run. It's what we expect for him, and it's what we expect the school to help us teach

overwhel..~

assertin..~   faith~   family c..~
child ch..~   ME - 12/..
has own ..~
faith~
ME - 12/..
persiste..~

peer com..~

autonomy..~ professi..~
communic..~
Frustrat..~
mode of ..~
                    parent k..~ child ch..~
consider..~
parent r..~
family c..~
parent r..~   uncertai..~
ME - 12/..   faith~
                    parent r..~

consider..~   family c..~
peer com..~

goals/ex..~
type of ..~

270

him too.

8

9　Je: K, I heard you talking a little bit about what kind of things you want him to be able to do. Kind of a short term vision. Do you guys have any ideas or goals about what you want for the future? Have you gotten that far, to thinking there?

0

1　N: I really do expect G to be the CEO of some Fortune 500 company. (laughter) I mean, you all laugh, but I am really serious. I tell him that every day. And, when he went to go and take his pictures, he went and told his teachers, my mama has to put my suit on me 'cause she thinks I'm the president. (laughter) He told his teacher his mom thinks he's the president. And I tell him, everyday, You're going to be just a little president. So, I set his expectations high, you know. Even though, you right now, if you look at it, it may look like he won't be able to accomplish those goals, but, that's what I have, that's the hope that I have for G. That's why I think that he has gotten as far as he has, because when he started in [other school district], G couldn't say a word, all he could do was slap himself upside the head, rock, hit his head on the wall, but the moment, there are certain things that I do on my own as well, but, when he started going to [other school district], that whole head-banging, it stopped, he started saying, you know, Mama, I want - they put him on the - it was an electronic device (Ta: what's that? that's what I want to talk to you about). It was an electronic device, it looks just like that (points at Netbook), it's a smaller computer, do you know what it called? Is it called a communicator box? That box, he would come and wake me up at 3 o'clock in the morning, come and wake me up, "Mama, I want ___" you know, he had to type in whatever. "I want cookies. I want milk." I got tired of that box, BUT when I took the box from him, it took him, I wanna say, a little bit longer than I expected, probably like 6 months, you know. And then after 6 months, he was walking around there, going "I want cookies" "I want..." you know.

2

3　L: He didn't depend on it.

4

5　N: He didn't depend on it

6

7　K: augmentative communication device

8

9　Ta: So do you think it held him back because he was depending on it, or

0

1　N: Because he wasn't saying a word.

2

3　Ta: Ok

4

5　N: He wasn't saying anything, but then, when he got the box, he started punching. That's what he thought he was supposed to do, to punch it hard, you know. And then, she would give it to him for like 3 weeks, she'd take it back from him, then he wouldn't say a word again. Then, she'd give it back to him, she'd take it away again, and that's when he started, you know, getting independent with his communication. And you know, this was very simple, it was easier than this little book that they had. What do you call it - the PECS book?

6

7　Je: The Picture Exchange Communication System?

8

9　K: That don't work at all.

0

1　Je: Anybody have a good experience?

2

3　Te; I don't even know what that is.

4

5   Ta: They, uh,

6

7   N: The school. The school had a good experience with G with the book. But the mama, it's too   — assertin..~
    much, it's too complicated for me. And I just told him, you know, we're going to stick with the   consider..~
    electronic box. And, it worked. It was the best thing. And now, you just have to talk to him. He'll   type of ..~
    say anything, whatever comes to his mind. He'll say it.

8

9   L: Yeah, the only thing that my son says is "coke." Coke, that is his favorite.   — child ch..~

0

1   N: And that's the thing, don't give it to him until he says, I want Coke.   — persiste..~

2

3   L: And see that's the thing, when the teacher was working with him, on doing his letter of his name   — child ch..~
    and putting it in order, he didn't want to. So, the teacher brought out his coke. So, then, he hurried   individu..~
    up and put his letters on...and I was like, yeah, it's amazing what he will do for a coke.   persiste..~

4

5   Je: Just a little motivation?

6

7   L: Yes.

8

9   Je: Um, is there anything else, about like your family, or your community, that affects the decisions
    that you've made? I've heard you guys say that you think Wyandotte County needs support from
    the community. Anything else?

0

1   N: Wyandotte County does need my mother. She, when I moved from Texas, she was telling me,   — perspect..~   approach..~
    teaching me, the things that I was doing wrong. She was like, this boy ain't talking because you
    allow him not to talk. You know, you're going to have to do differently. And like, the whole not
    dressing issue, my mother just took his clothes, threw them at him, and told him, you're not
    leaving until you put your clothes on. See, it's a different approach you know. And I kept on telling
    her, you're just on the outside looking in, it's not as simple as you are making it. But, unfortunately,
    she did come in and make it sooo simple you know. She made it so simple.

2

3   Ta: It's so funny that you say that, because that was like ,one of the biggest issues we had, when A   — identify..~
    was very young. You know, we had people like, "y'all are not doing this" or, you know.   perspect..~

4

5   Je: Like, people from the neighborhood, your family?

6

7   Ta: Family, like especially, my mother-in-law would come in and be like, "A can talk, y'all are just   — parent r..~   support ..~
    not doing such-and-such." And it was like, no, she has these issues, you know. And I always used   perspect..~
    to think its because they can't accept that she has autism, and so, they want to make her normal
    when she's not. But then when I stood back and looked and was like, well, she's doing it. And its so   — goals/ex..~   perspect..~
    funny because even when she first started going ot school, teachers could not control her. She'd   approach..~
    be biting, and scratching, and just...and they would, you know, the minute they would say, we're
    going to call mom, she'd just straighten right up. And it got to the point where, I got kind of
    scared, because, like are they thinking I'm abusing her, you know. I'm worried about the girl, is like,
    terrified when they say they're going to call mom. And I realized, it was just becuase I had a
    different approach. You know, they wanted to baby her, and say, oh, you can't do that. And I'm   — persiste..~
    like, oh, she can do that, and she will do that. And it's not a mean thing. I'm just like, I'm not
    accepting it because like, if she can do it, she's going to do it. And that was where, we kinda
    bumped heads, in the IEP meeting last year, here, it was like, they wanted to take her back to you
    know, 4 and 5 years old, and they were like, well she needs the picture book and that, and my   — parent r..~
    husband was like, no she doesn't. Because, the girl is at home putting popcorn in the microwave,
    she's combing hair, she's like, the other morning, she said, Mama can I go iron my shirt. And I was   — child ch..~
    like, you can't do that! And she was like, yes I can, I just need to run the iron over it. And I was like

to the point where, I wanna see you do it! Can you do it? And it's like, you realize, maybe I'm holding her back, and it's kind of one of those things.

8

9   N: And I can say, I do admit to a certain degree, I was holding G back. Because I didn't know what autism was. And she'll say, oh, hell both of y'all had autism if that's the case. Just give him them clothes. Make him put them on. And she was telling me, most of the behaviors, it's because you know, of me, and what I allowed him to do. Because when Nana comes to the house, G knows he can't get on the computer, and he knows he's got to go to his bedroom and make up his bed. And you sit back and you're looking at this, and it's like, what is it that my mother is doing, that I'm not doing? Is she beating him to death (laughter)? Cause I'm doing everything she tells me to do! It's just, he'll listen to her. And when, he feels like, I can get away with it a couple of times, with mom. But, my mom really was my biggest, strong supporter, in a lot of ways. And I didn't have that in Texas, and I really think it hurt him to a certain degree. There's a part of him that I can't get back, you know, but I just keep pushing him forward, you know.

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1   L: Yeah, I have a sister in law, and she keeps telling me you know, "Well I know this lady, and she put her son on the diet" on the gluten free diet, and you know it worked really good, he started doing this and he started doing that and I was like, you know what, I will try, but my son is one of those, is if, he don't get what he wants to drink he won't drink. If you give him something he doesn't want to eat, he's not going to eat. And I'm not going to starve him.

2

3   N: The diet, is good for kids who have health issues. The diet will not make the child talk, the diet will not change a behavior. The diet will keep the child from getting sick. That's it. That's my personal opinoin. If the child does not have any food allergies, then, leave it alone. it's not worth it.

4

5   Je: Yeah, I would say there's lots of different information out there, there's not any really concrete link between things...

6

7   L: And then I feel bad, like, do I want to do it? I just don't want to push it.

8

9   Ta: Cause you're always wondering, is it the difference between a particular food? Is that the reason? You know, if I could take just one thing out of her diet would she be fine? You know, and it's like, you can't, my daughter for a long time, she would not eat anything for a long time, except like, noodles or something.

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1   Te: My son loves ramen noodles. He'll eat ramen noodles, every day, for breakfast lunch and dinner.

2

3   Ta: And I make her, like, last night, she wanted to just eat meat. And I was like, you can't just eat meat. You gotta eat potatoes, or greens, which one is it? You gotta pick one. And so, you know "give me the potatoes" and she ate them you know. And it's like, you pick your battles. But, I mean, my daughter, she's gone from underweight, to I guess, not necessarily malnourished, but medically underweight, to overweight and it's just always like, it's like, okay, I'm just trying to get you to a healthy weight, and it's just one of those things you just keep plugging away. I kind of wrestled with that for a while too. 'Cause you would always hear about "I gave him the diet and he was completely cured." And you know, it's like, am I preventing something?

4

5   N: Let me say this, I mean, I will say that every child is different. I mean, I do know a ton of parents that have did the diet and it has made a major difference for their child. But, for me, and mine, the boy is still slapping himself upside the head and he is still on the strictest of diets. He don't have corn, he don't have wheat, he doesn't have milk, he's you know, soy free, chicken free, egg free, now you tell me what in the world can I feed that child? But, is he communicating? He says a whole lot of things but he's not age appropriate. He does a lot of things but it's still not age

273

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274

appropriate. So it depends on, the individual, the child. I say, I do encourage you to take it out, I'm going to say take it out, if you think it's a problem. But don't set your expectation that it's going to be a cure bullet, because it's not.

6

7 Ta: yeah...

8

9 N: It will not.

0

1 Je: You guys are really sharing some good insights with each other, and I really appreciate that. You guys have had the chance to share with each other and you're just leading me right into our next thing that I wanted to talk with you about. If you were giving advice to other parents in the same situation, if there were more parents at this table, if you could look back, 3 or 5 or 9 years ago, and you could give advice to someone in the same situation, what kinds of things would be important for them to know or actions to take?

2

3 Te: I would have to say, from my experience, the best thing for me was that he was diagnosed at 3 years old. And I think early treatment is the best treatment. And the earlier they can start receiving therapy the better it is. But, in my situation, I was given the diagnosis and just thrown out to the wolves. And, with my experience with what I have learned I pretty much have learned on my own. And with, my own experiences. So...

4

5 N: I think that's something that should be educated to us as well. Because I also, like you, was just given the diagnosis, but after I was given that diagnosis, I went ahead and went to another person that gave me the diagnosis and she gave me a list, an engine. She was like my google, of resources. But the thing was, I went to a professional, and the professional gave me nothing, and then I went to a, um, she wasn't even licensed. She just looked at my son, and she said yeah, he has autism, and this is what you need to do to try to get him services in the school. And this is what you need to do to try to help him, you know, with the illnesses that he has. You know, this is what you need to try to do. So I had a guide there, and I think that's one of the things my doctor should have told me. Yeah, he has autism, but, just because you call early childhood services, that doesn't mean they're going to recover your child from autism. He did not set my expectations. I was thinking, oh I'm going to call early childhood services, and I'm not going to have to deal with this no more. I mean, it's a life long issue. It's you have to, you have to do your own education, you have to do your own research. Because every single child is totally different. And, I didn't know that. I wasted a whole year of my baby's life thinking that the little services that were coming to my house, they're gonna do something.

6

7 Je: you have to be proactive?

8

9 Ta: Yeah, that's what I was going to say, one of the things we dealt with, was, people saying - cause my daughter, the first time we realized something wasn't right was when she was 12, maybe 17 months. She wasn't walking. Now, I didn't think anything of it, cause I have an older son, and he didn't walk till he was 15 months, and he, it's kinda weird, 'cause he needed some kind of special help when he first started school, and so, I'm always kinda thinking, like well, he might kind of have it too. But, he's almost like a savant, like, he's almost gifted. Like, he goes to S Academy now, but sometimes, when you're talking to him, it's like, his social skills are just a little off. You know, and so I'm like, maybe you're going to be the rocket scientist, you're going to do your thing you know. And so, but with A, it was like, I just kept seeing all of these things and it was like, you know, I kept feeling like something's not quite right, people's like, oh, well she just needs to be around other kids, and she'll start talking, you know, and like, the doctor wasn't even really saying anything to me, and even now I kinda wonder like, how did that slip through? I have like a 3 year old, and from the time he was born they're always telling you, these are the signs for autism, if they're not doing this, this and this, and its like, you know what to look for now, but back then, I didn't know what to

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look for and this was like, 11 years ago, and I thought, she likes to sit on the couch and like, (rock) and do this, because that's what she likes to do, and nobody told me, NO, she should be on the floor crawling around and pulling herself up and you know, and wanting to play with kids and so, I feel like the same way, I feel like I lost time because I didn't know what to look for.

0

1   N: But don't you think that the doctors and the school and the early childhood center, they need to have a connection somewhere. Don't you think it's like a little store, you know. And when you go to your doctor, he should be able to say, you know, you have autism, but I need you to call early childhood, and then early childhood needs to be able to communicate with the doctor as well, for you, because there are so many things that, like, my son had a lot of gastro issues, a lot of gut issues. Hell, I didn't know anything about no gut issues, I didn't even know there was such a thing as a GI specialist, okay, and you know, and nobody told me. So, this kid is sitting here, a year, without me knowing that there was a problem here. But, in Texas, that's what happened. When I got him to the school,there was a parent liaison, and she was an autism liaison, and she was an advocate for the parents as well. And she went to the doctors on my behalf. So she realized that he needed a feeding therapist, a speech therapist, gastro therapist. I mean, she wrote it all out. She presened it to the doctor, the doctor signed off on it, you know, but here, it's like, you are just doing everything by yourself. And..

2

3   Ta: It's like your grasping at straws, and you don't know, like. I know we had like an MRI done, cause I'm like, well is it in her brain? Like, what's the problem. And they were like, no, that's normal, and so...and actually, her babysitter was the one that came to me and said you know, she's just not doing things that other 3-year-olds should be doing. And she was actually the one that kind of pointed me in the direction to go and it was at that point where we were kind of able to get with the people that could really help us. And her first therapist, child psychiatrist, you know, he gave me all sorts of information about autism. And he was really the biggest help, in you know, in telling me, you know, this is what it is, and here's what you can expect, and these are the things that you need to do. And you can really feel like you're just lost out there, with nothing to grasp hold on to, if you don't have the knowledge. (1:10:55)

4

5   L: My son was diagnosed when he was 2 and a half, and the only reason why is because I have a sister in law, she's a teacher in the school district. And, um, she started off with her kids as having infant-toddler services, you know to come out with the kids, and make sure. So she was like, well maybe you should do that, with your first one. And so I said "okay" and that's what helped me. That's what helped me a lot. You know, with the teachers coming out, seeing where they should be. And by the time he was 2 years old, that's when they directed me to KU and they were the ones that diagnosed him. And they're the ones that helped me.

6

7   N: Well, but you know when they directed me to KU, it was like a big old joke. It was like a year, or 4-year wait...

8

9   Te: We went to Children's Mercy, and they seen me within about a month. I have a grandson that's a year younger than my son, and he was talking at 3, and my daughter was like, there is something wrong with my brother. And I was like, oh be quiet, there's nothing wrong with him! (laughs) And I said, oh, I better...so I made an appointment with Children's Mercy and they saw him within about a month.

0

1   L: I think mine took at least 4 months to get it.

2

3   Ta: Yeah, but see my daughter - she didn' t go to KU until she was like, 5 years old, and it was like...they were the ones that actually diagnosed it. 'Cause like, she was born in Wyandotte County, we lived in Wyandotte County, and then we moved after she was born. And so, we started with Wyandotte County Infant-Toddler. And I always looked at it from the aspect of, well she just needs

somebody to help her walk, to help her -

4

5 N: Yeah, me too.

6

7 Ta: I didn't understand that there was a bigger issue. I was trying to fight the little battles. Well, we just need her to walk! We just need her to talk! And once we moved to Topeka, it was like, yeah she's walking now, she's kinda slow to talk, but she's saying stuff, she's pointing she's grunting. Well, I didn't know, well no, she should be doing a heck of a lot more than that. And so...and then like I said it wasn't until she was like 3

8 and babysitter was like, yeah, she's got some for real issues that you've got to look into. And so, I feel like, for me, at the time she was diagnosed, I feel like, that wasn't really enough. I was like, okay, well somebody should have been telling me about this when she was like 6 months old because we could have been addressing some of these issues then. And I feel like, I feel fortunate because hers is not - the severity level is not as bad as a lot of other parents. And so I'm always appreciative of that. But I always still feel like you know, she maybe could have been better if I would have known more, you know. Now, could she be? I don't know, but you just always wonder.

9

0 Je: That's the feeling, right.

1

2 L: When he was a baby, everybody would say, oh, you know, he'll take time. But he did talk when he was a baby. See, my theory was like, 'cause everybody at that time, was blaming the immunizations.

3

4 N: I am that mother.

5

6 Ta: I did too.

7

8 L: And I was like, my son would say mom, dad, he would say toy, ball. He would say all that. But it was like, as soon as he got that shot, he was like down hill. And I, I really do, but people should...it's like, the government's hiding something,

9

0 N: But it's like out in the open, they know. You all know, it ain't a shock! (laughing)

1

2 L: By the time, I mean, I've always aimed it that way. And by the time it was time for him to go to school, they wanted him to get the shot. I refused. They were like, the only way you can refuse it and for him to go to school is you have to have his doctor sign it, you know. And I was like, okay. I went to the doctor, and she didn't agree about it. And I was like, well that's my beliefs, and I don't want him to have it. She was like, well, the only way that I'll sign this paper is if he's immune to it. So, we went to a lab, lab work, and he was immune to it, so she signed it.

3

4 Je: So it's kind of about bringing people to, getting involved with people who share your same perspective or have your same value or belief.

5

6 L: To this day, I still believe it. I was scared when I had my second one, to get it.

7

8 Ta: Me, too yeah. I had that conversation with the doctor. And he basically fussed at me and was like, you're basically putting her at more risk by not giving her the immunizations and I was like, I'm going to let you give her the shot, but if my daughter stops talking I'm going to kick your tail! (laughs) It was like...

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0 L: I waited until she turned 4, cuz you know she was talking, she was doing good. I videotaped her and everything! Just in case it happened.

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peer com..~

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2 N: Yeah! (laughs)

3

4 Ta: Yeah.

5

6 Je: So, kinda thinking about that, when my next kid came along, and things like that, so, like say, we got together and said let's make a road map for what parents should know and be thinking about as they're going into working with the school, what kinds of things should be on there? What do you think would be important to include? What kinds of information? I've heard some things, but I don't want to...

7

8 Te: I think communication is the most important thing. Between you an dthe teacher, and everybody that's working with your child. All the therapists, yeah.   communic..~

9

0 N: You have to be on the same page.   communic..~

1

2 Te: To be supportive of one another. You know, the biggest concern is for the child.   relation..~ individu..~

3

4 N: Right, and that's, if it's, if you're thinking about a map. If you take that child's name, and you circle it and start putting out little icons, to find out, what is needed.   individu..~

5

6 Te: Yeah, what works for that...

7

8 N: What works for that particular child. And that's what I think the IEP really needs to be. A circle,   individu..~
   child's name, and let's start throwing ideas out there to find out what he needs. And my son's   individu..
   biggest issue is behavioral issues, noncompliant issues. And that's just my biggest thing. And so   individu..~
   you say if we had to create a map, you know, my map would be um, just that individual child, you
   know.

9

0 Je: And the different individual things about them. Okay.

1

2 L: And I hope the other teachers, you know, at the school, they do talk to the other students about   communic..~
   autistic kids. 'Cause there'll be times when I go to pick up my son after school and they'll say "Hi   professi..~
   M" and it's like, do they actually know, you know, he's autistic. I just hope, but you know.   lack of ..~   peer com..~
                                                                                                           parent r..~ perspect..~

3

4 N: I think they do, because there was little girl out here and she was saying "Hi G! How are you   advocate..~
   today" and she was telling her mom "He has autism, he won't speak back!" And I was like, alright!
   Educate her! (laughter)

5

6 K: All your kids, do they go to regular class?

7

8 Moms: No..

9

0 K: Because M go to life skills. And I don't know if the other kids around, if they know about the Life   consider..~
   Skill class. Because Life Skills class, are just kids with special needs. And they don't have any
   contact with the kids around him. Like my daughter knows, because she goes to S too, because I   lack of ..~
   moved her, because she was in E. And her class I'm sure, all the kids knows her brother is autistic,   autonomy..~
   but I don't know if the other kids around the school know. And I think the kids should know, like if
   the kids are outside, playing, or if maybe they run away from the classroom. 'Cause I know M, if
   the door is open, he's gone! (laughter) He cannot see a door open. And a kid needs to know that,
   oh, this kid goes with the special class, he has special needs!

1

2 N: That's true, they do need to be educated, everybody.   autonomy..~

3

4 Je: Everybody.

5

6 N: Yes.

7

8 Je: So you guys would say educate everybody, communicate with everybody. Support each other. What else?

9

0 K: M used to go to the Children's Lodge, at St. Luke's Hospital, and one of the moms there, her son has Down's Syndrome, and when he started kindergarten, she made a paper, and all the kids in her class took home and tells the parents too. Can I get Down's Syndrome if I touch, and its information for them to have at home. And I was thinking we could make one for M too, to give it to...but in M's classroom, all the kids are special needs, they didn't have to worry about it, but we can do that to the kids around the school, and tell them about special needs.

             autonomy..~

             consider..~

1

2 N: And see if we had a community, an autism parent group, we could go into the schools and do just a special session on that. And invite the other parents to come out, with their students and open up that discusion. But, because we don't....

             autonomy..~   autonomy..~
             lack of ..~
             support ..~

3

4 K: There is not a lot of parents that know about autism.

             lack of ..~

5

6 Te: It's more common now than it used to be, so that is a good thing.

7

8 N: It is.

9

0 (others mmhmm).

1

2 K: But it still, M when we go to a restaurant, he likes to pull the chair, all the time, and I see people look at me, like, is he stubborn? And we pull him and push him, and it's just like, here he goes again. And it's like, M, stop. stop. And he look at me and laughs. He likes it this way. And I see how people look at me and "Mmmm. I think she's spoiling him."

             perspect..~   child ch..~

3

4 N: That's why I have business cards. So they know, don't ask me no questions. Cuz I'm telling you now.

             autonomy..~
             communic..~

5

6 Ta: I wish I had those business cards. I need them when we go to the restroom. My daughter has this thing with the ventilation. It's like, is that the fan? You know, and she needs the door open. So, you know, we're trying to block the door to the restroom, and that's not really appropriate when you're in public, 'cause you know, people are like, "what? You need to shut the door." So it's like, she's getting better, but still. (N laughs)

             child ch..~

             perspect..~

             monitori..~

7

8 Je: So I hear you saying, like, know your child, know what different things that they're going to need. I hear you guys giving great advice, for just navigating life in general for a child with autism.

9

0 L: I think everybody just needs to be educated.

             autonomy..~

1

2 N: Yeah, everybody needs educated. Especially everybody that has to something to do with the school, with the education system. If you have to go to a school because you have to pick up a child, that means a grandparent, or a security guard. The cross guard, everybody needs to know what autism, or just what special needs is, what does it really mean? And how do you do your part, as an adult, or as a student. Because I know, one of my friends, she had this really big issue with the bus driver. The bus driver would just pull over, because the child would keep standing up, she wouldn't sit down. And I'm like, "well where's the harness at for this child?" You know, there are other things that are missing in this piece here, and the bus driver don't know anything about

             autonomy..~

             autonomy..~
             professi..~

autism. And the bus driver, foolish enough to pull over and just wait. And she should know, as well.

3

4   L: Or if they have changes in the bus drivers, as well.

5

6   N: Right, and I'm expecting for my son to run a company, and so if they don't know what autism is, they're going to have to know, they're going to have to be educated! You know! (laughing)

autonomy..~

7

8   Je: So you guys gave a lot of good guidelines for this whole process. Is there anything you would say more specifically about the IEP. And you guys said before some of your feelings about how the IEP meetings were going, and how you felt about things people were giving you and the way language was being thrown around, and terms and that kind of thing. Is there anything else that would be more specific for, when you're in that meeting, when you're getting ready for that meeting, things you should know, things you should be ready for?

9

0   K: Um, one thing that I realized as we said, they already have the paper done. And I request some things to them, and I didn't receive the things that I request. I wish they could hear more from us. Because when M started, he was in Preschool 1. And all the kids were younger than him. And they moved him to Preschool 2, where the kids didn't have special needs, but it was, they have the developmental, they were much better than him. And it was the peer models for him, all the kids. He did a lot better things after he went to Preschool 2, and then when he went to kindergarten. I asked, I wish that he go at least one day or two days a week he could go to the regular kindergarten class where he could see, they have the peer models, that he can see. And they didn't hear me. Because I don't see him going to the regular class. I wish he could go because all the kids, actually, when I came at first to S P N, I was impacted, when I came to the class and I saw like wheelchairs, and all the kids with special needs, I was like, "Wow." My first impression was really bad because I was thinking that he could go to the regular kindergarten class, they took it off for the special needs class. But when I got there, he was in the special needs class, and they did not take it off at all, I was like, wow, what is that. And that was really bad. And the speech thing, like I said, I asked them to increase his speech, and they were like, "No, it's okay, 20 minutes, three days a week, it is okay." No, it is not okay. My son is not verbal, at all. He don't say anything. He don't say Mom, Dad, anything. I think they could hear us a little more too.

lack of ..~

child ch..~ autonomy..~ communic..~ ME - 12/..
consider..~

parent r..~
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system c..~

1

2   Te: I think it just has to do with this school district. (Others: It is. Mmhmm.) Because my son, he couldn't talk, he couldn't say anything. And I mean, they were big advocates for him. He got all kinds of therapy. (N: all kinds of services) and that, it was really helped him. That therapy. Without that therapy, I don't know where I'd be today.

advocate..~
system c..~

3

4   N: Right, and you know what else they had in [other school district] that I absolutely loved. They had after school care for kids with autism.

system c..~

5

6   Te: Mmmhmm. They had before and after school care.

system c..~

7

8   Others: Whaat? Really?

9

0   N: Right, there is no after school care for children with autism.

system c..~

1

2   K: It's not a place that I can go!

3

4   Te: Summer school was also something they were going to offer for him this year. But because we switched...

system c..~

5

6   N: And summer school is a big joke to me.

assertin..~
has own ..~

7

8   L: Its only 2 hours. It used to be 4 hours.

9

0   N: In Texas, it used to be 4 hours, okay.

1

2   L: Mmmhmm.

3

4   N: Because in Texas, we got 4 hours and it was 4 days out of the week. Here, it's so much of an   parent r..~
     inconvenience for me. Because, I'm not saying it's not long enough, I don't want you to think I'm   system c..~
     trying to pawn my child off. It's just like, I have to get arrangements for me to get off from work
     and do this and do that. I'd rather just home school him during the summer because its just not   lack of ..~
     worth it. There is no after school child care, and I think the school district should realize that these
     children with autism should have some kind of after school care. And it has just slipped their head.
     It fell through somewhere.

5

6   Ta: I see that lacking overall in the district. But I think some...I mean.

7

8   N: No, but see my normal child he goes to the, what is it called?

9

0   Je: KidZone?

1

2   N: Yeah.

3

4   Ta: They got that here?

5

6   N: Yes

7

8   Je: Not at every school,but...

9

0   N: Well I can get you the information.

1

2   Ta: See, my kids went to KidZone at the other school, but here, I'm like, there's nothing for them?
     They don't have an after-school reading program?

3

4   N: But see, I'm about to pull him out of the little KidZone 'cause he's like, those ghetto kids -

5

6   Ta: He throwing popsicle sticks and stuff?

7

8   N: he's coming home, saying stuff and I'm like OH hold on now, you can't say that. No, no.

9

0   Ta: I think, um, there needs to be more clarity as far as parents knowing what, I mean, you know,   mode of ..~
     every meeting, we get a copy of parents' rights. "Do you want a copy of parents rights?" No, I got
     a collection.

1

2   L: Well they said that there's a little newer,just because it has a table of contents.

3

4   Ta: One thing, I don't really know what kind of services my daughter is eligible for, or has the right   lack of ..~   confusio..~
     to recieve.   lack of ..~   type of ..~
                                                                                                                 mode of ..~

5

6   N: And you're not going to know that, unless you talk to the right parents.   identify..~   mode of ..~
                                                                                                                 perspect..~

7

8   Ta: Right, it's like. You're like, my kid gets that? LIke you know...

9

0   Je: So, like being able to list out all the different services that are out there in the district.

1

2   Ta: One thing that really turned me off when we went to her IEP meeting last year,and it was like a whole big fiasco. There were like 15 people at this meeting. And I was like, I've never even seen all you all. And it was like, I didn't even, I don't even really know, what all she's getting. And I'm like, well is she getting OT, how many times a week is she getting it,

            confusio..~
            lack of ..~
            overwhel..~
            uncertai..~

3

4   N: Are you serious?

5

6   Ta: What are you doing at the OT? At the other school, I knew that twice a week she was, you know, that she like, she had sensory issues. So they had adaptive PE where she was doing like swimming twice a week and stuff like that. And it's like, you really don't know what services are available in the district. I'm always thinking like, it's like, you know, I don't even know what services she could get. Or is eligible to get? I'm always wondering if there's another school she could be at, where she's getting other types of services that she's not getting now, so maybe if there was just a...

            lack of ..~
            system c..~
            lack of ..~
            lack of ..~
            system c..~
            type of ..~
            uncertai..~

7

8   Je: Or even if you knew about the services you could be asking about, requesting...

9

0   Ta: Yeah, yeah.

1

2   Lo: Every time I ask, you know, what other services? And they're like, well you can look up online,   *professi..~*

3

4   Te: And what if you don't have a computer?   *lack of ..~*   *parent r..~*
            mode of ..~

5

6   Lo: Yeah, and most of the time my computer's down, and I was like, come on y'all.   *lack of ..~*

7

8   N: They don't want to just come out and tell you.   *mode of ..~*

9

0   Je: So you'd rather have something you could hold in your hand and look at.   *mode of ..~*

1

2   L: Right. Like, a number.   *mode of ..~*

3

4   N: That's not personal! You need a personal connection!   *mode of ..~*

5

6   L: I know one of my meetings at the old Indian Springs, they gave us a booklet that I thought was helpful. They gave us a booklet of all the different dentist places, and they just had a lot of helpful stuff in there.   *mode of ..~*

7

8   N: You know, that was something that Diane A used to do herself. She used to just bring us all together and we would just talk. Right?   *mode of ..~*

9

0   Ta: Maybe if you had like an um, like for the kids that had the diagnosis. Maybe if there was someone in the district, like an autism specialist or advocate.

        lack of ..~   *advocate..~*
        mode of ..~   *mode of ..~*

1

2   N: We have one.

3

4   Ta: See?? You see? We've got one and I don't know.

5

6   Nel: See, Michelle, is over the autism program. You have Michelle, see the person I call for any type of issues is Olivia...Olivia..

7

8   Je: P?

9

0   N: Yes, see if I have issues with any of his verbal communication or his behavior, I always go to her, and she'll direct me to the right person. See I know she's not the person, but she'll direct me to the right person.   advocate..~

1

2   Te: Well maybe they need to be part of our IEP meetings.   advocate..~

3

4   Ta: Right, exactly, that's what I was going to say!

5

6   N: But that's what I was telling her, she was saying the 15 people, but those are the people you want in your IEP meeting. You want a team of people. Because those are the people that's going to come up and generate new ideas. Even students. I invite students just to come in, just to take a look at my IEP. Just ot make sure that we're not missing something. Because you know, G will get these IEPs these skills and he'll master them, and then he'll sit there for a whole semester doing nothing, and that's unacceptable. Let's go in and let's change it. So now, we're looking and we're re-evaluating the IEP every 3 months because there's no need for him to be sitting around, you know, touching nose, touching head, clap your hands. No. But now, since he's been over here, she's bringing me in every 3 weeks. And I'm like, go on girl. I like you! I like you! She's on it, you know. And that's what you really need. And it goes the same for the doctors. Because of all of his health issues, I make them meet once a year, as a team, to come together and see, what is our next step for him. So, you know. It's a full-time job, but you have to stay on it. But if they don't know anything about her IEP, then there's no need for them to be there. So, don't - those 15 people show up, you make every one of those 15 people say something, pertaining to her IEP. Get them involved, draw them in, find out, are they coming to her? Evaluating her? Because if they're in her meeting, they should be able to observe her. So, it's like, your son, what is the strategy of getting him to talk? Are we talking about a communicator box? Who are the people who can get it? All of those people that are on that - I have literally, 15 people that come to his IEP. But I make every last one of them tell me what has happened during the time that they ahve evaluated him. You know.

      communic..~
      mutual r..~
      perspect..~
      early in..~   Frustrat..~ goals/ex..~ individu..~
      assertin..~
      early in..~
      mode of ..~
      monitori..~
      professi..~
      assertin..~

      assertin..~   relation..~
      communic..~
      perspect..~
      professi..~
      assertin..~
      communic..~

7

8   Je: You are just really good at helping me segueway. (laughter) I'm trying to be really respective of your time, it's like, 6:25. So can I ask you guys to stay about 15 minutes extra. Because I've got some things I want to share with you guys as well. But you were talking about your role, as part of the team. And you know I heard you guys saying, have frequent meetings, it feels like a full time job, make everybody share, draw them into the process. How else do you see your role as part of that IEP team? What do you see is your job on that IEP team?

9

0   Te: Making sure that your child is receiving everything that he could possibly get. Just being an advocate for your child.   advocate..~

1

2   Je: Anybody else?

3

4   L: And I think if there's a certain subject to your child's needs, it should be longer. Not within like 30 minutes, 20 minutes a day, or 2 times a day. Take a whole day, take every Tuesday on speech. Take behavior, 2 days.   assertin..~ child ch..~ goals/ex..~ persiste..~

5

6   N: It goes back to individualized IEPs.   individu..~

7

8   Je: I get what you're saying, I just can't find a short little word for what you're saying.

9

0   Te: I think it falls under advocacy.

1

2   Je: Maybe you're talking about flexibility, or asking people to be more flexible. I don't want to put words in your mouth, but... K, how do you see your role? We've kind of talked about this all

throughout, but anything else that you would add about how you feel like you fit into the team, or what's your job on the team?

3

4   K: Be a parent. Be with him, and teach him at home.   ▪ mutual r..~

5

6   L: Be patient.   ▪ parent r..~
                                                                                             persiste..~
7

8   K: Yeah be patient.   ▪ persiste..~

9

0   L: You need a lot of patience.   ▪ persiste..~

1

2   Ta: I guess if we're looking at it like a team, I would see myself as like the coach. I need to be   ROLE
      managing every aspect, you know, to make sure nobody's dropping the ball. And so it's like she
      said, what's going on over here. Because you know I think, so many times where parents go wrong   parent r..~
      is we kind of, let the school basically take the initiative. And we kind of just go along with it, like, if   assertin..~
      it sounds good, you know, and, not to say anything bad about the school, or whatever, but I   autonomy..~ parent k..~
      mean, they only spend so much time with your kid. You're the one, you spend the most time, you   parent r..~
      know, with that kid. You know what that kid is really able to do, and you really need to step up and
      say, okay, you know, no, or, and, it's okay for you not to always agree with what they suggest. And   assertin..~
      that was something I really had to get over. Because, you don't want to step on people's toes, and   communic..~
      you feel like, well they're trying to help my kid, you know, they're trying to do their job. BUt at the   relation..~
      same time, it's like, no, mm-mmm, you really just have to...

3

4   Je: kind of encourage?

5

6   Ta: Yeah, and know that you really do have rights. That you don't have to accept. Like if you go   assertin..~
      into that IEP meeting and you decide a month down the road, okay, this isn't working. Say, okay,   parent k..~
      we all need to come back together. Because that was one thing that I'm really starting to   persiste..~
      understand now. That, at any time, I can call an IEP meeting, and say, we need to meet, cause it's   assertin..~
      not working. And so, the district has the responsibility to educate. And we really need to take   mutual r..~
      advantage of that and do what's best for our kids.   parent k..~

7

8   Je: Anybody else have anything to add? That was kind of our last big question for the evening.

9

0   L: Can I ask something?

1

2   Je: Sure:

3

4   L: Do any of your kids have sensory issues on socks?

5

6   K: My kid has them on shoes.

7

8   L: on shoes?

9

0   K: He takes them off all the time. He cannot keep his shoes on.

1

2   N: I gotta tell my baby to keep his shoes on!

3

4   Te: My son doesn't have trouble with that.

5

6   N: Girl, he would take them shoes off all the time!

7

8   Ta: Now my daughter does have sensory issues, but she has to smell stuff and taste stuff. She

needs to always know what stuff smells like.

9

0   L: Well, the company that I work for, they're called smart knit socks. And they're for sensory, for kids, who have a thing with like, any strings inside the socks or anyting, and those don't have any strings inside.

1

2   Je: I was going to say, I know a little girl here at [school].

3

4   Ta: I don't know that my daughter would...

5

6   Je: I do have one more question for you guys. We were talking about a road map, you know, about what that would look like. How do you think using a guide or a map like that would change your relationship with your team?

7

8   N: It will make you more prepared. Because I guess right now what I'm hearing is that they already have the IEP designed or created for our child already. But if we had something, or let's just say this road map, that we are able to look at it, far ahead of time, then we will sound a little bit more educated, going into the IEP meeting, instead of surprised, in awe, and shocked, just not....I guess, in my IEP, because I'm very active in my IEP, it's different. There is no more of that. L was totally different for me. I had a really bad experience at L. But now, its more of a, it's tailored to G. But I had to learn how to tailor it to G. And with me not knowing what works for him, I had to depend on the school. And that's where a lot of my frustration was. But the more that I educated myself on the IEP and the whole process, it became a little bit easier, and I had that map. I had other parents to tell me. I had angry parents too. They would tell you, you know, you gotta fight! You gotta go in there with your guns. And I was like, Oh, shoot I don't wanna do that! But you know, knowing it, made it a lot different.

9

0   Je: That knowledge makes a big difference.

1

2   Te: See and like now, you don't even get your IEP to read before the meeting. So you don't even have time to review it. And I mean, I'm a slow reader, and I really have to concentrate. I cannot be reading while people are talking, you know. I don't get any knowledge that way.

3

4   L: and you need to let your teachers know that they're supposed to.

5

6   N: that's the law

7

8   Te: Oh, I didn't know that. I've never seen my IEP before...

9

0   L: Say, send it to me a month before.

1

2   N: Let them know that you need it.

3

4   Ta: 'Cause you can get intimidated. 'Cause they're like, and you know the one teacher is sitting there, like, 'cause they've been at school all day. I'm trying to read, and it's like, do you have any questions, well, it can be an intimidating thing.

5

6   L: Usually, they try to rush it. And I tell them, next time you need to schedule it for me to have it for a whole hour, hour and a half.

7

8   N: That's why I started, having her record it. Because she was kicking us out and we had to call her in advance, to say that we were coming up to the school. I made her record the sessions, and that's when it started taking like 2 hours, just for an IEP meeting. But it gets that way, you know.

lack of ..~   assertin..~
mutual r..~
parent k..~
parent r..~

lack of ..~   educatin..~

assertin..~   educatin..~
parent k..~
perspect..~

confusio..~   mode of ..~
educatio..~   parent k..~
Frustrat..~   parent r..~
individu..~   professi..~

assertin..~

parent k..~

parent k..~

assertin..~

advocate..~   parent r..~
assertin..~

autonomy..~
parent r..~
professi..~

parent r..~   professi..~

assertin..~
parent r..~
professi..~

9

0 Je: Abbey, did you have anything that you wanted to add, or follow up on?

1

2 Ab: I've just been typing furiously! Just typing my little heart out.

3

4 Je: Well, the good thing about this is that we'll get together again. So, you know, we've heard what you all have to say, Abbey's been typing furiously. I've got all my notes up here that I've scribbled.

5

6 N: I have a question for you. You guys are compiling all of this data. Are there going to be any changes made? Do you guys have the power to make any changes? Or is this just data that we're collecting and we're going to present this to other parents?

7

8 Je: So we talked about having two sort of, forums, that we're working with. With KU, and then also with the school district. As part of getting permission with getting permission to do research in the school district, you're able to um, come back and share it with like the school board or with various people in the district. And you guys know that I'm an employee of the school district, so I'll bring this info back to our director of special ed, and my supervisor and share that with them. And kind of the second aspect of this, from all of these conversations, if you guys are interested in being a member of our Advisory Board, is what we're calling it, it's a smaller group of parents, and some people from the school, who are working together, and we want to create something, like a map, something like that. And the final product by the end of the year, be some kind of map or guide. I'm hoping that next year we can take it on a test drive. Maybe you guys want to take it to your IEP meetings or give it a try. Share it with other parents, and other school districts. The hope is that this isn't just us all talking, but that we get another step forward together. The other piece of it being a project at KU, is that we'll present it to people in our school psychology program, it'll be part of something that I hope that I can publish, um, and like, in some kind of journal that, typically, its something for people that work in schools and professionals that would look at something like that, but um, so it gets out there into the field so that other people who work in schools, it could be something that they're like "ahh this is something that I might want to use" so that's the kind of long term goal. So, I hope that helped to answer your question.

9

0 N: It did.

1

2 L: Will we get a copy of all this?

3

4 Je: When we get back together in February, we will have some kind of summary for you guys. Probably, some kind of visual map that kind of, lays out the themes that we heard you all talking about, that kind of revolves around those 4 questions. And there may also be a kind of typed up, short summary kind of thing. To go along with that summary idea, Abbey and I reviewed some of the research that's out there right now, from parents who've been sitting in meetings like this and talked with people and kind of shared about what their experience has been and so, we wanted to share that with you and see whether you think "Yeah, this makes sense for me" or "No, this doesn't sound anything like what it's been like for me." So, um, if you guys can just, and there's kind of several pieces, and we'll just pass it around there. The first thing that we kind of looked at, was, you know, different parents were asked about their experience with the process of making decisions. Kind of the steps they took. So some of the things we talked about. Um, some things that came through was that they thought educating yourself was really important. Considering the available options that are out there, talking with people that you trust. Getting second opinions. Considering the context of your community and your family. Understanding that there are emotions involved in all this. Thinking about other relationships that htey ahve. Seeking out that balance, and trying to prioritize what's important. I know we hit on a lot of these. I didn't know if there were any of these that struck you more, or that didn't seem to apply at all.

5

6   K: One thing that, I, we have struggled with, it is things that M could not have after he is 18. We have now a savings account for him, and we heard that we can't have that after he is 18. We can't have a savings account for him after he is 18, because if he has money, he will not get support from teh government. It is something that maybe we need to know better. Like the things that we needed.

                system c..~
                type of ..~
                uncertai..~

7

8   N: I didn't know that.

9

0   K: You did not know that? Because like now, I cannot get any help from the government because me and my husband we make more than what they say we need to do. And if we have money saved, they will first need to use all that before the government will give them anything. And like another thing, I was trying to talk to someone. I need to have a will, and I don't know how to do it! I don't have anybody to help me make a will, because, especially me, I'm not from here. I don't have anybody here. I don't want him to be here, if I'm dying. I want him to go back to my country where I have my family to take care of him. And I need to have this on a will and I need this information.

                system c..~

                type of ..~

1

2   N: You can get online and get an attorney who speaks Portuguese.

3

4   Ta: My husband is an attorney and he does wills. And so, um, you're Portuguese.

5

6   K: For me it has to be in English, I know. But they have to know, that me and my husband if we die, I want him to go back to Brazil. And I plan for my family to take care of him.

                type of ..~

7

8   Ta: I think that, you know, even with the government resources, I was fortunate because when my daughter was diagnosed, I worked for the state, as a disability examiner, so I knew that she was eligible to receive benefits as a disabled child. But if I didn't have that kind of job, I wouldn't have known.

                parent k..~

9

0   Te: What kind of benefits?

                system c..~

1

2   Ta: Its basically, well one program I think what she was referring to, is SSI.

3

4   Te: I went and applied, they said uh-uh.

5

6   Ta: Really?

7

8   Te: I don't qualify because I make too much money.

                parent k..~
                system c..~

9

0   Ta: Yeah. One is a need based, and there's also one SSDI,

1

2   K: is that a Wyandotte County one?

3

4   Ta: I'm not sure, this is through Social Security.

5

6   K: I know the county does have one but they just cut off. This one doesn't go for the income, just for the disability. They need ot go there, look at him, do the test, yeah the county does too. But they just cut off. BEcause the economy's so bad.

                parent k..~
                system c..~

7

8   L: Only thing we can get is a handicap sign.

                parent k..~
                system c..~

9

0   Te: Really.

1

2 N: You can get a handicap sign?

3

4 L: Yeah. I think down at the disability.

5

6 N: Do I have to get a doctor's excuse?

7

8 L: You just have to sign a paper that your child's autistic and they're not known for safety. Like, when we go to stores, they just run.

9

0 Ta: Yeah, 'cause my daughter will dart.

1

2 L: I'll park right in front. Especially at the mall.

3

4 Te: Now, not to change the subject, but does anybody know where the Social and Rehabilitative Service office is? For Wyandotte County?

5

6 Ta: It's close to like, 5th and State,

7

8 Je: It's like close by right downtown, yeah.

9

0 Ta: If you get on State, and just go all the way down. You'll run into the Towers.

1

2 Te: Is it like the courthouse, like on 6th and Ann?

3

4 Ta: No, its like, between State and Washington Boulevard. So like, if you get on State, and just keep on going past the federal courthouse. You'll run right into it. You'll get to the point where you can't go any furthe rand that building will be right there.

5

6 Je: Lots of information sharing. This next paper I'm passing around is like, factors, the different things people are considering when they're making decisoins. So, parents of kids with autism and kids with other kinds of disabilities that talked about different factors that they were weighing. We talked about some of these things. We talked about things about the school district or the school system they were working with. Aspects of their family, hearing different people's opinions, different people's approaches, thinking about their own child and what's unique about them. Thinking about the community that was out there for them, things about the community that was out there. The roles of different people on the team, which we kind of touched on as well. Parents talked about a balance of power, which I heard you guys alluding to as well. Feeling like there were differences, when you're coming into your team. Thinking about perspectives of other people, looking at what different information was available. Different resources that are out there. You guys were just talking about the law and different things that affect it. Parents talked about being stressed, being stressed about different things in their lives. They talked about values, which we kind of touched on, again, those emotions played a role. Feeling like they needed to trust someone else. Kind of those personal beliefs, and goals that you have for your child. I think we kind of hit on all those, but that's for you guys to have and just kind of review and think about.

7

8 L: I have an aunt that's been helping me to find something. And she did come up with something. This is just a piece of paper that I brought in. It's supposed to be a cure for autism.

9

0 N: Do your research. You can spend all the money, and all the everything. This is a lot of money.

1

2 L: 30,000 dollars for the first dose.

3

4 N: And I've talked to 5 parents, Five parents who said it did not work. However, there is a handful

of them who said it does work. It's going to be the individual child. You know, what I"m doing, it only costs me $80 a month.

5

6 Ta: What is that?

7

8 N: homeopathy. I do homeopathy for my son. Mm-mmm. I used to do biomedical to the T. I was spending to the tune of like $3000 per month. and I went from $3000 per month to $80/month is working so much better.

9

0 L: See, and my child's not on medication.

1

2 N: My son is not on medication either. I am 100% totally against medication. Now, the little girl that I keep, she's real severe and she's on medication, and she's on medication. But it doesn't really help her.

3

4 L: I've talked to the lady at that place. And she said the only place that they would do it is either in Mexico or in the Caribbean.

5

6 Je: I was going to say I don't know that there's a lot of support out there...

7

8 L: No.

9

0 Je: for it at this time. I haven't heard of a lot of kids who've had that. It would definitely be something to thoroughly check out and really make sure that it's safe.

1

2 L: Yeah, I read this stories and they sound so good. And I told my husband, for me to do something like this and I would literally have to talk to these parents acutally, see these kids, and do my own research. 'Cause a lot of stuff could be written just by doctors just because they want money.

3

4 N: Let me tell you what I've learned. Recovery is different for every body. You know, there is another mother, her child, I keep her child, and she is so severe. And she says G is so recovered. But not to me, he still has long way to go.

5

6 Je: I heard a parent once say that she wouldn't do any treatment on her child that she hadn't tried herself first. So you know, like a diet, or something like that. Like, she would put herself on the gluten-free diet first, and see how it felt for her. And try different things like that. I mean, I haven't heard a lot of people who have done that, but she kind of, you know.

7

8 N: See, thats a good way of looking at it. I've done the biomedical for myself. I've done the diet for myself. I do homeopathy for myself. So, and homeopathy has been the most beneficial than anything else. All that money I spent, Oh, what a fool. (laughs)

9

0 Je: And at the same time, it's going to be, it's going to be different for every parent and every child. And that's what I wanted to talk to you all, because you've had different experiences.

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2 K: Like you said, trying things. I don't try, but after I have so many problems with M's pediatrician when he was born, I changed him, and his new pediatrician, she does have autistic kids of her own. I don't know if you guys know her, Deborah W---? She's in Overland Park. And I think it's much easier. Like normally, she first prescribed to him Prozac. And they're using it a lot more in kids with autism. And I first thing said, did you try it with your daughter? I wanted to know. You, as a mom, not as a doctor anymore.

3

4 N: what was that?

5

6 K: Prozac. Yes some kids with autism, they're using Prozac.

7

8 Te: My son doesn't take any medications.

9

0 N: Ask her if she's using it for herself, Now if she's using it for herself, I would run!

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2 K: I tried, I give it a try, because she said for her daughter it worked. I gave it a try, but for M it didn't work. I am against medicine too, but like, he is on Focalin for ADD, and it's helping him so much.

3

4 Ta: Focalin, my daughter um, she was taking it and um, we're in between therapists right now, because it's a narcotic. You have to have a doctor's script. They won't just refill it without a prescription. And so...

5

6 Je: It's a more updated version of an ADHD medication, yeah.

7

8 Ta: And so we tried so many different medications. And the Focalin really helped. But see she got to the point now where, I wouldn't make her take medication during the summer. Because my thing was if she didn't need to be on it I'm not going to make her take it. And she went into this whole, it makes my throat hurt! I don't know what that's about. But the teacher told me that she didn't even know that my daughter wasn't taking medication. And before I even agreed I asked the doctor, could she get to a point where she wouldn't need it? You know, could she be able to sit in class and focus? And that was the bigget thing. I'm not trying to control her behavior, because I don't like the way she's acting. My thing is, if it's preventing her from actually learning. They can't teach her because she's like everywhere. Then, to me, that's a good reason. But like now, her teacher you know, she says she sits in class and she does her work. Well then, I'm like, well then I don't see the need to give it to her. And I'm not saying she won't ever need to be on something again at some point it's just, you know, medication is, so many people look at it as a quick fix. But if they're able to function without it, then I'm like, don't use it. Because, she was on one medication, and she would constantly sleep. She wasn't eating. She wasn't herself. She was like just like a zombie. And I was like, okay, this isn't right, you know, and so we really had to kinda work through a lot of stuff to get to it.

9

0 Je: And frequently that's a lot of how it is, especially with kids. Is just a lot of trial and error. And I was, um, sorry guys I have just a couple more. I think you guys are looking at the challenges. And we're talking about things that made it harder. These are things other parents have said. They talked about um, a difficulty with resources and services, feeling like they had enough options. They felt like they had challenges with the policies and practices.

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2 Te: I don't have that one.

3

4 Je: You don't have that one? (figuring out page) So you guys can see on the front there, that service continuity, like making that connection between doctor and home and school. And on the back, having stress, feeling challenges, stress with their team members, and feeling like they don't have enough knowledge. Which, definitely heard you guys saying. So, it's kind of cool for someone like me, who's looked at and read a lot of that stuff, to sit down with you and hear some of the same things, hear your take on it. And then, parents were also asked what was going to help them make decisoins, kind of facilitate decisions. Things that made things go easier. Which here, K, there's that one. Do you guys have that facilitating one? Okay, well that's where I got myself off then. You guys all have? So again, kind of as we talked about challenges there were, kind of as a flipside to that we talked about was, there were some things that went well. They felt like there was

continuity. Felt like they sought it out in different ways. Or, they heard it from different people. Or there were things about hwo they were sharing it with each other. Or from a parent to a team, here's all the information I have to share. They talked about preparing in advance, which you guys touched on as well. You know, having that IEP 2 weeks before or 4 weeks before. Having that person that they could count on and trust. And again, just touching again on those personal beliefs, and at the end of the day, keeping the child at the center of it all. I don't know if those felt true for you, or if there was anything else, any other thoughts. About those challenges and things that were facilitating. I think everyone is at their limit, as far as being tired of talking. The last one just has to do with parents' roles in IEP meetings. Abbey, do you want to talk about this one?

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6   Ab: Yeah,sure I wasn't paying attention I was checking my spelling. (chuckles) Um, this I just put together that your role can be defined in a variety of ways. Just what the law says about your role, and some barriers you may face in defining your role with your team. And what your role is in the IEP meeting. Just kind of broad. Real broad strokes. I think we've discussed it more in depth, but...

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8   Je: But I think, some of what we've talked about here, is kind of echoed in you know, in what we're hearing from other parents. You guys are definitely not alone in some of these experiences. We just really need to work on moving forward.

9

0   N: Is it that the rules don't meet the children's needs? That's probably what it is. The rules? The laws? Is not meeting really meeting their IEP needs.

1

2   Je: That's what we were looking for, is reactions to this. I think it's a really interesting insight, that it's the law that's not adapting as it should. That maybe there are people that want to do more of this, but it's hard when the law seems like it's interfering.

3

4   (Yawns)

5

6   Je: Any closing thoughts on that, and talking about this summaries. I'm glad that we get to get together another time.

7

8   N: I know that I need, for G, I need to have a parent that is very well educated about the IEP that is very educated about hte IEP process and invite them into his IEP meeting. But I've had to learn about how to do certain things for myself. I dont' know if it's always necessarily the right approach. But you know, you live and you learn.

9

0   Te: That L S support group that I used to go through, a couple of those ladies like know the IEPs like the back of their hand and they offered to go with me. BUt, I just didn't take the offer. Because I just felt more satisfied than they did. I mean, I didn't have a problem with what they were telling me. Of course, I was new. So... you know.

1

2   N: I guess that's how I felt.

3

4   Te: So, you know I've been - over there, I've been pretty satisfied we'll just have to see how this year plays out. Anyways...

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6   Je: Do you guys have any other closing thoughts or comments.

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8   Te: No, this has been really a good experience for me, and I've really enjoyed this.

9

0   N: Thank you

1

2   Te: I feel a little bit more at ease that, getting to talk to other people other parents, of children

with autism. You don't really get to do that very often.

3

4   N: I think that's so needed, for our children to grow. Because if we had just given them what we
     know, then they'll never grow. But if I can take bits and pieces from her, and her experience, and
     you, and apply it to what they need, then, G will be very successful in life. He will be...

5

6   K: the president!!

7

8   (laughter)

9

0   N: He has to be! 'Cause his mama's not going to accept anything less.

1

2   (laughter)

3

4   Je: Well I'm going to go ahead and turn this off, and I've got a couple of things to give you guys.