

# Knowledge-to- Action Guides

## *Preparing Families to Be Partners in Making Educational Decisions*

Ann Turnbull | Nina Zuna | Joo Young Hong | Xiaoyi Hu | Kathleen Kyzar

Shea Obremski | Jean Ann Summers | Rud Turnbull | Matt Stowe

Marlene Wyatt is the mother of three children ages 5 and under. Her middle child, Liz, who is approaching her third birthday, has an autism spectrum disorder. There is never an unclaimed minute at home or work for Marlene. Her husband frequently works overnight and weekend shifts. Marlene works as a custodian at the local school.

The family receives an early intervention home visit once every 2 weeks; the practitioner gives Marlene suggestions for following through with routine-based early intervention, especially related to communication and social skills. The family's service coordinator, who has a caseload of 96 families, recently e-mailed Marlene regarding an upcoming transition planning conference to decide on what preschool Liz will attend once she turns 3. The service coordinator said this would require a new evaluation and that many people would be at the meeting. She also referred to "Part C and Part B." Marlene read the notice and was at a loss and exasperated: "What the heck is Part C and Part B? Why can't they communicate with me in plain English?" Marlene has no idea how to prepare for the meeting so that she can make the best decisions for Liz.



Stand for a moment in Marlene's shoes and consider how you would juggle your everyday responsibilities and still find time to prepare for the transition meeting. From the time it was first authorized as the Education for All Handicapped Children Act in 1975, the Individuals With Disabilities Education Improvement Act of 2004 (IDEA) has been revolutionary in terms of its affirmation of the importance of parents participating equally with educators in making decisions about their children and thereby holding educators accountable for benefiting the child (A. P. Turnbull, Turnbull, Erwin, & Soodak, 2006). Did Congress have any idea how much responsibility Marlene and other families should have to be equal decision makers and accountability monitors?



IDEA continues to impose significant new responsibilities on parents (H. R. Turnbull, Stowe, & Huerta, 2007). In fact, never before has so much been expected of parents with children with disabilities in terms of their roles as educational decision makers in partnership with professionals (see box, "Parent Responsibilities Under IDEA"). Further, the Supreme Court has held that IDEA does not entitle parents to recover expert witness fees (*Winkelman v. Parma City School District*, 2007) and that, as a general rule, parents bear the burden of proof in due process hearings and subsequent appeals to federal or state court (*Schaffer v. Weast*, 2005). The statute and cases in effect require parents to be experts in special education practice and law (H. R. Turnbull et al.)

But how can parents become experts in special education, and help make good decisions about their children's education programs? Knowledge-to-action (KTA) guides are one resource, providing families access to top-tier knowledge on evidence-based practice; this knowledge can help parents carry out their responsibilities to participate with educators in making decisions about their children—and in holding educators accountable for providing beneficial interventions.

### **Defining Evidence-Based Practice**

The education of students with disabilities should incorporate evidence-based practice. The Council for Educational Children (CEC) has identified 10 standards that define a *well-prepared* special educator (CEC, 2008b). Standard 4 states that special educators should "possess a repertoire of evidence-based instructional strategies to individualize instruction for individuals with exceptional learning needs" (p. 3). Clearly, this standard was influenced by the No Child Left Behind Act of 2001 (NCLB) and IDEA, both of which emphasize use of scientifically based research. NCLB declares a national purpose of improving the academic achievement

### **Parent Responsibilities Under IDEA (see 20 U.S.C. § 1415)**

- ❖ In the case of a dispute with the local education agency (LEA), parents must provide legally sufficient notice to the LEA concerning their perception of the educational problems that their child is experiencing, the solution that they propose to resolve the educational problem. Additionally, they must attend a mediation prior to a due process hearing in an attempt to resolve the problem without needing to go to a full due process hearing.
- ❖ Parents must disclose all evaluations and recommendations that they intend to use in an administrative (due process) hearing.
- ❖ Parents must allow the LEA to cure any IDEA defaults before recovering attorneys' fees.
- ❖ Parents must risk not recovering fees when they initiate an administrative (due process) hearing.

of students by "ensuring access of children to effective scientifically based instructional strategies" (20 U.S.C. § 6301(9)) and defines *scientifically based research* as "research that . . . involves the application of rigorous, systematic, and objective procedures to obtain reliable and valid knowledge relevant to education activities and programs" (20 U.S.C. § 7801(37)). IDEA calls for scientifically based instruction (20 U.S.C. § 1401(c)(5)(E) and (F); 1414(a)(5) and (6)) and for the use of related service and supplementary aids and services that are based, to the extent practicable, on peer-reviewed research (20 U.S.C. § 1414(d)(1)(A)(IV)).

Further, CEC's Professional Standards and Practices Committee's *CEC Practice Study Manual* (2008a) outlines a process and associated rubrics for evaluating the state of evidence for special education practices. The gold-standard criterion for group experimental and quasi-experimental design includes:

#### AT LEAST

One strong causal design study that is well implemented with positive effects

#### AND

One moderately strong causal design study that is well implemented with positive effects

#### FROM

At least 2 independent research teams

#### AND

No strong causal or causal approximating design studies that are well implemented with negative effects (CEC, 2008a, p. 31)

Does this mean that educators and parents are restricted to only using scientifically based methods/instruction for students? What happens if sufficient scientific evidence is not available to guide instructional decision making? Whitehurst (2003) responded to these concerns by broadening the focus, and offered a construct of *evidence-based education*, which he defined as the integration of professional wisdom with the best available empirical evidence in making decisions about how to deliver instruction.

There are two critical aspects of this definition. First, by referring to the "best available empirical evidence," Whitehurst (2003) implied that sufficient rigorous, systematic, and objective knowledge is not available on every topic, particularly at the gold standard of experimental designs. Thus, educators are responsible for using research that is currently the *best available* even if it does not meet the highest bar of being rigorous, systematic, and objective. Second, Whitehurst referred to *professional wisdom*, which he defined as judgment that individuals acquire through experience. Whitehurst's advocacy for combining the best empirical evidence with experience-based knowledge is especially important when research is unavailable or does not include in its sample population the characteristics of learners and learning environments for which education is being planned.

There is a difference between "best available research" and "top-tier research." It is exceedingly difficult, if not impossible (given the constant publishing of research), to conduct literature reviews and research syntheses that are so thorough that they identify the very best available research. It is daunting to ever be sure that one truly has the *best*. It is less difficult and therefore more practical to identify the top-tier research, namely, the research that meets high standards consistent with the *CEC Practice Study Manual* (CEC, 2008a). *Top-tier research* should be as current as possible, preferably published within the last 10 years, and include diverse samples (rather than relying on primarily European American, middle-class participants).

To supplement research and experience-based knowledge, a third source of knowledge, especially within the field of special education, is policy—IDEA, its regulations, and courts' interpretation of them. For example, IDEA is highly prescriptive about how practitioners and families plan for transition from preschool to early childhood education; it specifies the timing of the transition conference, the people who must be invited, and the nature of nondiscriminatory evaluation that is appropriate to consider (20 U.S.C. § 1436 (a) and 1437 (a)(9)(A)). Thus policy (IDEA) creates the framework within which practitioners and families apply Whitehurst's (2003) approach: best available research and experience-based knowledge—to which might be added *knowledge about policy*. Knowledge about each of these three

for children and youth with disabilities and their families (Buysse, Wesley, Snyder, & Winton, 2006).

### Models of Knowledge Translation

If Marlene Wyatt had relied on Google to search the Internet to learn more about her rights and how she could best prepare for the transition conference, and if she had used the key words "parent rights," she would have found over 44 million references. Even narrowing her search to "parent rights and special education," she would have had over 23 million sources to consider. She would have found almost 60,000 documents if she had entered "parent rights, special education, and early childhood transition." How can someone like Marlene, who usually does not even get to her computer until after 10:00 p.m., possibly locate top-tier research, relevant evidence-based knowledge, and current policy to support her role as a decision maker with and monitor professionals serving her child?

Many families of students with disabilities utilize Google to locate information to assist with educational decision making. Although Google is not the top choice for researchers seeking evidence-based information pertaining to education, it is often families' primary alternative. Families often cannot afford or do not have free access to peer-reviewed education journals that publish evidence-based studies, unlike researchers and practitioners who are employed by universities and school districts that offer free subscriptions.

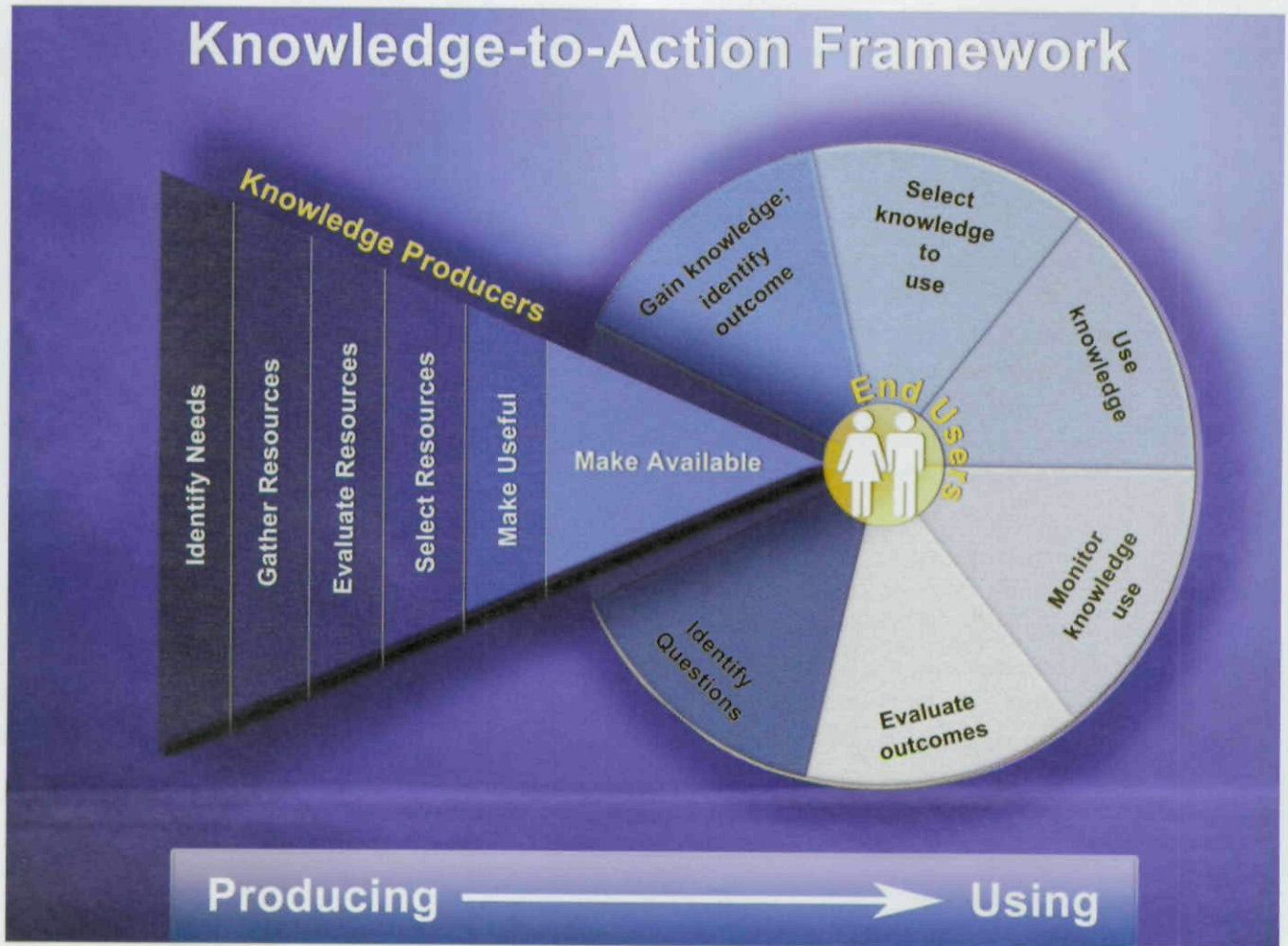
### Evidence-based practice is . . . a decision-making process that integrates top-tier research, relevant experience-based knowledge, and current policy for improving outcomes for children and youth with disabilities.

areas provides the foundation on which practitioners and families should base decisions about a child's education. *Evidence-based practice* is defined, therefore, as a decision-making process that integrates top-tier research, relevant experience-based knowledge, and current policy for improving outcomes

Given this circumstance, families must sift through thousands of Web sites in hopes of finding evidence-based knowledge.

To deal with the *infoglut* (Denning, 2006, p. 19) of available information, the health field in particular has emphasized the process of *knowledge*

Figure 1. Knowledge-to-Action Framework



Adapted with permission from "Lost in Knowledge Translation: Time for a Map?" by I. D. Graham, J. Logan, M. B. Harrison, S. E. Straus, J. Tetroe, J., W. Caswell, et al. (2006). *The Journal of Continuing Education in the Health Professions*, 26, 13–24.

translation. Sudsawad (2007) compiled an informative compendium of knowledge translation models. One of the models she reviewed, the Knowledge-to-Action Process Framework (Graham et al., 2006; Graham & Tetroe, 2007; see Figure 1) has relevance to knowledge translation in education.

### Knowledge Funneling

Figure 1 illustrates the process of moving knowledge through a funneling process so that it will be useful and relevant to end users—namely, practitioners and families. Funneling is necessary to prepare top-tier knowledge, relevant experience-based knowledge, and current policy in formats that inform but do not overwhelm.

*Identify Needs.* Identifying needs from the outset ensures that resources address end users' priority questions

and preferences. For example, on the topic of positive behavior support, the needs and priority questions of educators and families (e.g., how to prevent aggressive behavior toward others on the playground) are important to identify from the outset.

*Gather Resources.* There are many for-profit and nonprofit organizations and funding agencies that publish useful resources; however, not all of these resources are readily available for download over the Internet. Some materials are only delivered to individuals who are on an organization's mailing list; some documents are unpublished and are available only upon request, whereas other materials have to be purchased. The multiple locations of resources and costly fees create "silos" of knowledge which constrain practitioners' and families'

access to and use of the knowledge. Again, resources must align with end users' priority needs and preferences and be cost effective. For example, a Google search using the search term of *positive behavior support* identified over 4 million links. It is impossible for educators and families to sift through all of these links to find the best available knowledge to respond to their needs and answer their questions. Clearinghouses (e.g., the Institute of Education Sciences' What Works Clearinghouse, <http://ies.ed.gov/ncee/wwc/>) review the seemingly countless sources of knowledge in order to locate the ones that provide the most promising content.

*Evaluate Knowledge.* The current evidence-based practice movement holds that it is necessary to "separate the wheat from the chaff" to secure

**Table 1. Components of Knowledge-to-Action Guides**

Topic	Experience-Based Knowledge	Research	Policy
<b>Stage 1</b>			
Planning Transition From Early Intervention to Preschool	Video in English and Spanish Parent quotes/action steps from Community of Practice 4 family stories 4 state education department family-friendly guides	1 literature review Highlights of 2 qualitative research articles 1 audio interview/transcript with researcher and parent	3 policy advisories of IDEA and court cases with action steps PowerPoint presentation on IDEA Four R's – script for policy responses in planning meetings
Advocating for Care Coordination	3 family stories (print and audio) Audio interview with physician Family perspectives/action steps from Community of Practice (available in Chinese) Links to key national family networks Link to templates for developing care notebook	Highlights of 2 survey studies Data charts from major national survey	Policy advisory on federal and state laws Model policy from national organization Interview with parent and professional leader on policy reform
Providing Emotional Support to Families Through Parent to Parent Programs	Video of Parent to Parent support Link to Web site of national Parent to Parent network	Highlight of quantitative research synthesis and audio interview/PowerPoint of lead researcher explaining synthesis method and findings Highlight of qualitative research synthesis Highlights of one quantitative and qualitative study Link to research section of Parent to Parent Web site	1 policy advisory on parent rights to services to obtain emotional support and action steps
<b>Stage 2</b>			
Customized Employment	Link to an online video Link to customized employment success stories Link to 2 videos for purchase	Highlight of 1 quantitative study Highlight of 2 descriptive studies	Policy Highlight of Supreme Court decision Link to identify local One-Stop Centers Link to article on employment policy
Preschool Transition for Asian American Family	Audio interview/transcript with a Korean mother Parents quotes/action steps from Community of Practice and a summary on interview with a Korean mother 1 state education department family-friendly guide in 5 Asian languages Link to Web sites on Asian American and disability resources	2 literature reviews Link to research-based book	Glossary of special education and basic legal terms in English, Chinese (simplified and traditional), and Korean Link to a Web page of special education law book Link to <i>English-Hmong Special Education Glossary</i> (Minnesota Department of Education, 2008) Link to parents' guide on preschool transition in 7 Asian languages

*continues*

**Table 1. Continued**

Topic	Experience-Based Knowledge	Research	Policy
<b>Stage 2 Continued</b>			
Cochlear Implantation: Making Decisions About Communication	Link to a national parent organization Link to cochlear implant simulations Links to 2 documentaries of families who have children with cochlear implants highlighting their decisions about communication Links to 2 blogs Link to a comprehensive guide for families considering transitioning their child from sign communication to oral communication	Text interview with researcher PowerPoint presentation summarizing a literature review Highlight of a mixed-method research study Highlight of a qualitative research study	Policy advisory highlighting relevant portions of IDEA Policy advisory summarizing recent court decision Link to a 2-page ASHA Issues Brief on cochlear implants and IDEA
Being a Partner of Professionals for Your Child: Korean American Parents' Preparation for an IEP Meeting	Links to 2 Korean American parents' stories (in English and Korean) Korean American parents' suggestions/action steps in terms of IEP meetings Link to a special education information booklet for Korean American parents in Kansas (available in Korean)	Highlights of 2 qualitative research articles Link to Web site of Korean resources Link to a blog	Policy advisory on parent rights in English and Korean Links to resources of 2 state education departments Policy advisory highlighting 10 brief steps before an IEP meeting (in English and Korean) Policy advisory on preparation for a child's IEP meeting (including self-questions and examples of appropriate language)

Note. IDEA = Individuals With Disabilities Education Improvement Act of 2004; ASHA = American Speech-Language-Hearing Association; IEP = individualized education program.

high quality in the available knowledge. Criteria need to be established to locate research syntheses, if they exist—and, if they do not exist, to locate current, rigorous literature reviews and research studies. In addition, experience-based knowledge must be evaluated to determine appropriateness and relevance; policy knowledge must be current and applicable to practitioners and families.

*Select Knowledge.* After evaluating resources, select and highlight those that meet the criterion of top tier in quality and applicability. For example, resources on positive behavior support that are evaluated and rise to the top standard of quality must then be selected in identifying the best available.

*Make Useful.* Having top-tier knowledge is insufficient if the knowledge is packaged in a way that it is difficult for end users to understand. Consistent with these users' needs for knowledge, resources should (a) be succinct in

"getting to the bottom line," (b) have scaffolded levels of knowledge to appeal to a wide range of users, and (c) embed action steps leading users to application. After selecting the best available knowledge, that knowledge needs to be made useful in terms of preparing it in user-friendly formats that meet the preferences of educators and families.

*Make Available.* Finally, top-tier knowledge resources must be formatted to match end users' ultimate preferences. Useful resources are only useful if educators and families can access them.

### Action Cycle

Knowledge translation involves action to secure an outcome (Landry, Amara, Pablow-Mendes, Shademani, & Gold, 2006; Orzano, McInerney, Scharf, Tallia, & Crabtree 2008), yet guides to action are the exceptions (Lavis et al., 2003). The action cycle on the right side of Figure 1 connotes the level-of-

use process that is required by end users in applying knowledge to improve outcomes. The cycle depicts the process or steps of acquiring knowledge and using it to take action: identify priority questions, gain knowledge and identify outcomes, select knowledge to use, use knowledge, monitor knowledge use, and evaluate outcomes.

### Developing Knowledge-to-Action Guides

At the Beach Center on Disability of the University of Kansas, we have developed a series of KTA Guides (available [http://www.beachcenter.org/wisdom\\_based\\_action/default.aspx](http://www.beachcenter.org/wisdom_based_action/default.aspx); see Table 1 for topics and content). Our goal was to implement the definition of evidence-based practice that we have presented in terms of integrating top-tier research, relevant experience-based knowledge, and current policy in order to enable practitioners and families to make informed

### Bottom-Line Action Steps: Transition to Preschool

- ❖ Recognize that transition from early intervention to preschool is a process rather than an event. Attend and participate actively at every step along the way. Don't be afraid to ask lots of questions.
- ❖ Consider the short- and long-term outcomes that you envision for your child and your family. This will help define more clearly what services and supports your child and your family may need in the school setting in order to reach future goals.
- ❖ Recognize that children with disabilities, including those with very significant disabilities, can still be successful in inclusive settings when staff are well prepared and when supplementary supports and services are provided.
- ❖ Keep open lines of communication with early intervention and preschool professionals during the transition process. Ask them about supports they can provide—having information in advance of meetings, having an opportunity to visit programs that are being considered for your child, and having a key person (including a veteran parent) to guide you through the process.
- ❖ Talk with other families about what their experiences have been with the transition process and find out if they have any tips or advice for you to consider.
- ❖ Know that you are an active decision maker in the transition process. Understand your rights as a parent under IDEA (the federal education law in the United States) and find out applicable state and local policies by contacting your state Parent Training and Information Center or by asking the early intervention or school program with which you are working.

Reprinted with permission from "Knowing and Acting on Your Rights: Planning Transition from Early Intervention to Preschool," *Knowledge-to-Action Guides: Transition to Preschool—Transition Knowledge Bank*, the Beach Center on Disability, [http://www.beachcenter.org/wisdom\\_based\\_action/transition\\_to\\_preschool\\_\(general\\_version\)/transition\\_knowledge\\_bank.aspx](http://www.beachcenter.org/wisdom_based_action/transition_to_preschool_(general_version)/transition_knowledge_bank.aspx). Copyright 2009 by the Beach Center on Disability.

decisions to improve outcomes. In implementing this evidence-based practice construct, we also have the goal of following the process of knowledge funneling as demonstrated in Figure 1. In a nutshell, we are seeking to not only "talk the talk" of funneling knowledge in order to identify and implement evidence-based practice but to "walk the walk" as well.

We vetted the template we developed in a national meeting with leaders from family, academic, and federal agency communities, securing the leaders' feedback on this general approach to knowledge funneling. The Transition to Preschool Guide we discuss in this article would assist Marlene in her preparation for the transition planning conference; outlining our steps in developing KTA guides provides direction to educators in developing similar materials.

### We are seeking to not only "talk the talk" of funneling knowledge in order to identify and implement evidence-based practice but to "walk the walk" as well.

#### Stage 1: Template Development

Our online KTA Transition to Preschool Guide includes a summary of legislative and judicial background on IDEA (including definitions of terminology and explication of legislative requirements) and links to the three knowledge sources: experience-based knowledge, research, and policy. The summary page presents and addresses specific questions, overviews the topic, and recommends bottom-line action steps collectively based on research, experience-based knowledge, and policy. These other pages of the KTA Guide (Transition Knowledge Bank, Experience-Based Knowledge, Research, and Policy) supplement

material in the summary with additional documents and videos. Following the link to the KTA Guide's Transition Knowledge Bank will expedite Marlene's search for knowledge and provide her with practical action steps (see box, "Bottom-Line Action Steps: Transition to Preschool"). The Transition Knowledge Bank also recommends and provides a link to a comprehensive resource on the topic (i.e., *Tools for Transition in Early Childhood: A Step-by-Step Guide for Agencies, Teachers, and Families*; Rous & Hallam, 2006).

#### Experience-Based Knowledge.

Families report that they especially value insights from others who have faced similar situations (Ainbinder et al., 1998; Mitchell & Sloper, 2002; Ruef & Turnbull, 2001). The KTA Guide's Experience-Based Knowledge page offers Marlene the options of (a) watching a video (in English or Spanish) about families' perspectives on transition planning; (b) reading quotes from discussions on the topic, linked to action steps (from the Beach Center Family Support Community of Practice discussion about preschool transition; see box, "Perspectives on Transition Planning"); (c) reading four stories from families about the suc-

cesses and challenges of their participation in transition planning; and (d) reading four (three in English and one in Spanish) booklets on transition planning developed by state departments of education. Reading all the documents and viewing the video takes about 90 minutes; our experience is that most families pick and choose a few options and reduce their reading time to about 30 minutes.

In order to locate relevant experience-based knowledge, we sought advice from leaders of national family organizations and faculty who have conducted research and engaged in product development about preschool transition. Our criteria included thor-

## Perspectives on Transition Planning

"My experience has been primarily with Part B programs. However, as a special ed director we worked with the ECI/Part C agency for the transition of a student. I am not clear what the Part C regulations are and what are Texas regulations. In Texas, the ECI Agency must tell the school about students 90 or 120 days before they turn 3 (with parent consent). Then 60 or 90 days before the child's birthday, the ECI Agency and the school must offer the parents a meeting to discuss options for the child when they turn 3. Unfortunately, in some cases these timelines were not met. The ECI agency generally said that the parents would not give consent or were slow in agreeing to the meeting."

"Over the years, I met with many parents before their child turned 3 and explained their options and took them to observe programs. While this did not remove all of the parents' stress and concerns, it was a start. It also started the process of building a positive relationship with families. The IEP meeting had to be held on or before the child's 3rd birthday. Even if the regulations are different in your state, the parents should be requesting a meeting with the school through the special education department to discuss options."

"Go and observe different classrooms, if possible, unplanned, from the classroom's perspective, then you get to see what is really happening in the classroom and not what is happening when they know a visitor is coming. I am a preschool teacher and the transition is SO important that I think observing and even talking to the teachers to find out what you think is the best fit is very helpful. Once (her) family has found the fit, they can communicate with that teacher ahead of time to ensure that everything (she) may need is ready for her."

"I would like to offer another suggestion. I think a valuable resource is another parent who has been through and survived the transition. Perhaps the ECI agency would know of some other parents that transitioned in the past that would be willing to 'mentor' an incoming parent. Also, many states have parent to parent groups that could match an experienced parent with the new one. Observing the different possibilities is especially helpful, and when you can add an experienced parent to the mix, it really helps."

Excerpted with permission from "Parents Speak Out: Family Perspectives and Suggested Resources for Transition Planning," the Beach Center on Disability, [http://www.beachcenter.org/RealStories/Documents//Wisdom\\_ParentsSpeakOut1\\_March081.pdf](http://www.beachcenter.org/RealStories/Documents//Wisdom_ParentsSpeakOut1_March081.pdf). Copyright 2008 by the Beach Center on Disability.

oughness in addressing key issues, inclusion of examples representing a diverse range of children and families, respectful tone regarding families, succinctness, and willingness of a developer to provide permission for online posting. The only new resource we developed was the collection of family perspectives, drawn from Beach Center Family Support Community of Practice

### Action Steps

- *Request a meeting with the school through the special education department to discuss options.*
- *Make an unplanned visit to the preschool classroom.*
- *Talk with other parents who have been through the transition process.*

discussions. There are many excellent resources available through a variety of sources, yet Marlene and other families simply do not have the time and established networks to locate these resources.

**Research.** The Research page presents relevant top-tier research, a literature review and two qualitative studies. The linked Research Highlights sum-

marize the studies, describe the "bottom line," and then lay out salient promising action steps, key findings, methods, and related literature citations. Families participating in focus groups had indicated that they preferred the implications (promising action steps), findings, and method, in that order, rather than the format typically used in research articles (introduction, method, results, and discussion, including implications).

The Research Highlight template is succinct, reader-friendly, and oriented to the bottom line. Both documents suggest additional resources; one (presenting results from Hanson et al., 2000; see box, "Key Findings From Research Highlight") also provides families a link to practical products developed by the research team. Without such a link, how would Marlene and other families know that these products exist?

The Research page also includes a 25-minute audio interview (with embedded photographs) of a nationally acclaimed scholar on early childhood transition and a parent leader. The interview, which can be downloaded to a podcast, reviews key findings from research and how these findings can be best implemented. In 1 hour, families can listen to the entire interview and read the three documents.

**Policy.** The Policy page includes links to two Policy Advisories of two to three pages each (one comparing Part C and Part B and the other providing an overview of parent rights and roles in transition) and a summary of two major court cases on early childhood transition. Each of these includes links to other documents such as the IDEA statute and full opinions from courts.

The Policy page also includes a PowerPoint specifically designed for family audiences and an innovative resource (see Figure 2) developed by Chuck Noe (n.d.), an active member of the Early Childhood Family Support Community of Practice. In online discussions within the Community of Practice, families and practitioners discussed roadblocks that families most often encounter in navigating the special education system and suggested




## Key Findings From Research Highlight

- ❖ Most families find that transition is a specific and isolated event rather than the coordinated process that it should be.
  - Most families lack knowledge about the nature of their rights and how to act on those rights. They say practitioners made the decisions without any real participation by the family. "But what the teacher did was she just rang me up. She said, 'We need it. We're going to do a transition meeting. Can you make it Thursday afternoon?' And I said, 'Yes.' And, you know, I never thought to say, 'Oh, what does that exactly mean?' . . . So I didn't know what it [the meeting] was about."
  - Professionals often describe the process as involving too much paperwork.
- ❖ Families expressed concerns about the transition from early intervention services to school services.
  - There seemed to be a shift from more of a family-centered approach in early intervention service agencies to more of a system-centered approach in school settings. "The communication that I had with the teacher and her affiliates [at the early intervention service agency] — the eye lady, the speech lady — they were there. They were available. They made the time. . . . And I always felt reassured through the whole program." (pp. 285-286)
- ❖ Families strongly emphasized the importance of communicating and exchanging information before the transition planning meeting.
  - Some families were very well prepared, and others were not. One service provider described how she prepared families: "I have just spent parts of my home visits going over some of that paperwork with the parents and trying to describe the process. And I have just done it a little at a time. You know, there are so many pieces of paper that need to be signed and need to be reviewed." (p. 286)
- ❖ Families believed they were given very few choices in the types or locations of preschool services.
  - Children who had participated in inclusive early intervention services were more likely to also experience an inclusive preschool environment.
  - About two-thirds of the families said that the professionals made the choices; the other third said that they were able to choose.
  - Parents generally tended to be most interested in finding a specialized program for their child, rather than an inclusive program.
  - Inclusive options were not available at all locations. One professional said, "I always feel caught in the middle, because I want to tell them, yes, your child should be in an inclusive [setting] . . . [but] there's not one out there that I can offer them." (p. 287)
  - The child's behavior and level of development were major factors in deciding the child's preschool placement.
  - Language and cultural issues also strongly influenced preschool placement.
  - Families had different opinions about their child's levels of development as compared with others in the class.
- ❖ Factors in success included viewing transition as a process, starting early in planning for transition, exchanging information between families and professionals before the transition planning meeting, holding an informational meeting before the transition planning meeting, visiting preschool programs, bringing the child into the process (for example, placing a photograph of the child on the table or using a video to provide important information), and having a key person (another parent or a professional) to facilitate or guide the process.
  - The extent to which parents were equal partners in the process was largely determined by whether or not professionals welcomed their involvement. "Having a buddy system so that . . . we have parents who've just transitioned into preschool and have gotten adjusted can serve as mentors to parents that are coming in, and even if possible to be a mentor to a family . . . as to what to expect." (p. 289)


*These researchers translated their findings into six booklets containing practical guidance for parents. You can learn more about those booklets from the publisher ([www.brookespublishing.com](http://www.brookespublishing.com)).*

Reprinted with permission from "Research Highlight: Planning for Transition," the Beach Center on Disability, [http://www.beachcenter.org/Wisdom/ParentRights/Wisdom\\_RH1PlanningforTransition\\_Feb08.pdf](http://www.beachcenter.org/Wisdom/ParentRights/Wisdom_RH1PlanningforTransition_Feb08.pdf). Copyright 2008 by the Beach Center on Disability.


**Figure 2. Chuck's Four R's**




**Chuck's 4 R's: Remark, Recall, Reason, Response**  
*Help for Parents and Education Advocates to Respond to Remarks they hear from Schools*




**The Remark:**  
"We don't need to write that down in the IEP. We'll do the best we can to provide the service." (Or, that goal can be accomplished through instruction already embedded in the curriculum). "We'll get back with you on how it works."



**Recall the Law**  
"The IEP means a written statement for each child with a disability that is developed, reviewed, and revised in a meeting" in accordance with sections 300.320-300.324 300.320(a). The IEP must include "a statement of measurable annual goals, including academic and functional goals designed to meet the child's needs that result from the child's disability to enable the child to be involved in and make progress in the general education curriculum." 300.320(a)(2)(i)



**The Reason:**  
Unless good ideas are actually written down in the IEP, the services will not be required by law to be implemented. Regardless of good intentions, be sure that the service is put in writing including who and when it will be provided.



**The Response:**

- "I'm not comfortable with not including this in the IEP. If we feel, as a team, that this service/goal will help meet my child's needs, let's go ahead and write it into the IEP now. That way, we'll make sure it's not overlooked or forgotten—especially by people who aren't in this meeting today but will be implementing the IEP"
- "If we don't agree that this service/goal is necessary, then let's continue discussing it. We can meet again to finalize the IEP."

Reprinted with permission from *Chuck's 4 R's: Remark, Recall, Reason, Response. Help for Parents and Education Advocates to Respond to Remarks They Hear From Schools*, by C. Noe and the Beach Center on Disability. (n.d.). Retrieved from [http://www.beachcenter.org/Wisdom/ParentRights/Four\\_Rs.pdf](http://www.beachcenter.org/Wisdom/ParentRights/Four_Rs.pdf)

responses that families might make. Chuck then provided leadership in a wiki to connect these roadblocks to the relevant IDEA regulations and prepare a script that parents might use in IEP meetings. To date, Chuck and the online community have developed 12 "Four R" guides for families.

### **Stage 2: Preparing Doctoral Students to Develop KTA Guides**

Stage 2 of our work focused on preparing doctoral students to develop KTA Guides. We led a doctoral seminar in our Department of Special Education focusing on how research and theory

could best be used to enhance family quality of life. Each student developed a KTA Guide on a topic tied to her expertise (see Table 1, Stage 2). The class involved current readings in knowledge translation, families' preferences for accessing resources, and Web 2.0 technology. Assignments were scaffolded throughout the semester, focusing successively on each part of the KTA Guide.

Table 2 describes lessons learned from Stage 1 that helped us guide the doctoral students in creating their knowledge banks. At the end of the course, the students supplemented this

list with suggestions based on their learning experiences.

The students completed a reflective questionnaire focusing on their challenges, successes, frustrations, and "lessons learned" in developing the KTA Guides. Highlights of student comments on what they learned from this experience include the following:

Probably the skill that I was able to develop was how to think in terms of what information will be useful to families. Too often, we don't think about the work we do and how it will impact the beneficiaries.



I have developed the skill to use reader-friendly language, polish my ideas to a specific topic, and develop action steps for the specific situation.



I learned that forming personal relationships with authors is incredibly helpful in getting information. I guess I always felt that was overstepping my bounds, so now I know it is one of the best ways to learn. I plan on continuing to make relationships with people in my field who are the most knowledgeable about my interest.



I think many of us learned how many amazing resources are available if only you take the time to research them out.

### **Next Steps**

We will continue to develop KTA Guides on a wide array of topics. Our team anticipates developing KTA Guides particularly related to the challenges that individuals with significant disabilities and their families face as they transition from high school to postsecondary activities. We anticipate that families' (and educators') access to top-tiered knowledge combined with action steps can help remediate the dismal postschool outcomes that students with significant disabilities now experience (Eaves & Ho, 2008; Wagner, Newman, Cameto, Garza, & Levine, 2005). A major limitation of our

**Table 2. Lessons Learned From Knowledge-to-Action Guide Development**

<b>Summary Page</b>	<p>Review the knowledge throughout the KTA Guide and identify bottom-line action steps as succinctly as possible.</p> <p>Include the most comprehensive resource for people who seeking depth and breadth.</p> <p>Format in an attractive way that will draw readers into the Guide.</p>
<b>Research Page</b>	<p>Seek first to locate a research synthesis that provides an in-depth quality review of top-tier research.</p> <p>When a research synthesis is not available, seek to locate a literature review that includes a critique of studies.</p> <p>When neither a research synthesis nor literature review is available, conduct a literature search of research in the last 5 years using key words.</p> <p>When conducting a literature search, identify 2 to 3 researchers who have published most frequently on the topic. Read their work first and search the reference list at the end of their articles.</p> <p>Contact the 2 to 3 leading researchers on the topic and ask them to nominate what they consider to be the top-tier studies that answer the specific question.</p> <p>Before writing a Research Highlight, sit down with someone totally outside of the field and explain the research study to them. Focus on what is useful and make your explanations clear.</p> <p>Ask one or more top researchers if they would agree to an interview over the phone or through email.</p> <p>Identify major research centers that focus on the question.</p> <p>Recognize that it takes many drafts to translate research language into family-friendly language. (It is harder than you think.)</p>
<b>Experience-Based Knowledge Page</b>	<p>Ask family and academic leaders for suggestions of videos, stories, manuals, and other resources that include the collective knowledge of families and educators who have successfully implemented practices tied to the target question.</p> <p>Identify major centers funded by the Department of Education and other federal agencies that are relevant to the target question and explore their Web sites.</p> <p>Send an e-mail to the 6 to 8 top individuals nationally whose names have come up in the literature or in other sources and ask them for their recommendations of resources that are especially strong that contain experience-based knowledge.</p> <p>Don't get side-tracked and dazzled by a fun resource or video clip. Stay focused on your specific question.</p> <p>Use the free social bookmarking Web site, Del.icio.us, to aggregate favorite Web sites or online documents into one account.</p> <p>Partner with a couple of families (or other end users) seeking knowledge about the specific question. Listen to families from the outset about their questions and the nature of knowledge that would be helpful to them. Then ask the families to review the KTA Guides and provide feedback on their clarity/usefulness.</p>
<b>Policy Page</b>	<p>Locate and synthesize relevant regulations from IDEA and other key federal legislation</p> <p>Review leading policy Web sites including Lexis Academic (if you have access to a university library), Cornell's Legal Information Institute (<a href="http://www.law.cornell.edu">http://www.law.cornell.edu</a>), Thomas for Legislation (<a href="http://thomas.loc.gov/">http://thomas.loc.gov/</a>), and Government Accountability Office (<a href="http://www.gao.gov/">http://www.gao.gov/</a>).</p> <p>Review Wikipedia entry on policy and consider the search words and references at the bottom of the Wikipedia entry.</p> <p>Conduct a Google search using various terms specifically targeted at the policy topic to locate documents written in a family-friendly manner.</p> <p>Translate legalese into clear language that is easier to read and then link to the legal documents for users who want original sources.</p>

present work, in light of the KTA Framework depicted in Figure 1, is that most of our work to date has related to knowledge funneling; we are eager to now work on practices of how best to coach families to implement KTA Guide action steps.

Knowledge is power—but only when the powerful act knowledgeably and the knowledgeable act powerfully. Our KTA Guide approach enables families, such as Marlene Wyatt's, to be more powerful because they will have the ability to combine knowledge with action.

## References

- Ainbinder, J., Blanchard, L., Singer, G. H. S., Sullivan, M., Powers, L., Marquis, J., et al. (1998). A qualitative study of Parent to Parent support for parents of children with special needs. *Journal of Pediatric Psychology, 23*, 99–109.
- Beach Center on Disability. (2008, February). *Research highlight: Planning for transition*. Retrieved from [http://www.beachcenter.org/Wisdom/ParentRights/Wisdom\\_RH1PlanningforTransition\\_Feb08.pdf](http://www.beachcenter.org/Wisdom/ParentRights/Wisdom_RH1PlanningforTransition_Feb08.pdf)
- Beach Center on Disability. (2008, March). *Parents speak out: Family perspectives and suggested resources for transition planning*. Retrieved from [http://www.beachcenter.org/RealStories/Documents/Wisdom\\_ParentsSpeakOut1\\_March081.pdf](http://www.beachcenter.org/RealStories/Documents/Wisdom_ParentsSpeakOut1_March081.pdf)
- Beach Center on Disability. (2009). *Knowledge-to-action guides*. Retrieved from [http://www.beachcenter.org/wisdom\\_based\\_action/default.aspx](http://www.beachcenter.org/wisdom_based_action/default.aspx)
- Buyse, V., Wesley, P., Snyder, P., & Winton, P. (2006). Evidence-based practice: What does it really mean for the early childhood field? *Young Exceptional Children, 9*(4), 2–11.
- Council for Exceptional Children. (2008a). *Classifying the state of evidence for special education professional practice: CEC practice study manual*. Arlington, VA: Author.
- Council for Exceptional Children. (2008b). *What every special educator must know* (6th ed. rev.). Arlington, VA: Author.
- Denning, P. J. (2006). Infoglut: Overload of cheap information threatens our ability to function in networks; value-recognizing architectures promise significant help. *Communications of the ACM, 49*(7), 15–19.
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism Developmental Disorders, 38*, 739–747.
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., et al. (2006). Lost in knowledge translation: Time for a map? *The Journal of Continuing Education in the Health Professions, 26*, 13–24.
- Graham, I. D., & Tetroe, J. (2007). How to translate health research knowledge into effective healthcare action. *Healthcare Quarterly, 10*(3), 20–22.
- Hanson, M. J., Beckman, P. J., Horn, E., Marquart, J., Sandall, S. R., Greig, D., et al. (2000). Entering preschool: Family and professional experiences in this transition process. *Journal of Early Intervention, 23*, 279–293.
- Individuals With Disabilities Education Act, 20 U.S.C. §§ 1400 *et seq.* (2008).
- Landry, R., Amara, N., Pablow-Mendes, A., Shademani, R., & Gold, I. (2006). The knowledge-value chain: A conceptual framework for knowledge translation in health. *Bulletin of the World Health Organization, 84*, 597–602.
- Lavis, J. N., Robertson, D., Woodside, J. M., McLeon, C. B., Abelson, J., & The Knowledge Transfer Study Group. (2003). How can research organizations more effectively transfer research knowledge to decision makers? *The Milbank Quarterly, 81*, 221–248.
- Minnesota Department of Education. (2008). *English-Hmong Dictionary of Special Education: English-Hmong Special Education Glossary*. Retrieved from [http://education.state.mn.us/MDE/Learning\\_Support/Special\\_Education/Evaluation\\_Program\\_Planning\\_Supports/Cultural\\_Linguistic\\_Diversity/001162](http://education.state.mn.us/MDE/Learning_Support/Special_Education/Evaluation_Program_Planning_Supports/Cultural_Linguistic_Diversity/001162)
- Mitchell, W., & Sloper, P. (2002). Information that informs rather than alienates families with disabled children: Developing a model of good practice. *Health and Social Care in the Community, 10*, 74–81.
- No Child Left Behind Act of 2001, 20 U.S.C. §§ 6301 *et seq.* (2001).
- Noe, C., and Beach Center on Disability. (n.d.). *Chuck's 4 R's: Remark, recall, reason, response. Help for parents and education advocates to respond to remarks they hear from schools*. Retrieved from [http://www.beachcenter.org/Wisdom/ParentRights/Four\\_Rs.pdf](http://www.beachcenter.org/Wisdom/ParentRights/Four_Rs.pdf)
- Orzano, A. J., McInerney, C. R., Scharf, D., Tallia, A. F., & Crabtree, B. J. (2008). A knowledge management model: Implications for enhancing quality in health care. *Journal of the American Society for Information Science and Technology, 59*, 489–505.
- Rous, B. S., & Hallam, R. A. (2006). *Tools for transition in early childhood: A step-by-step guide for agencies, teachers, and families*. Baltimore, MD: Paul H. Brookes.
- Ruef, M., & Turnbull, A. P. (2001). Stakeholder opinions on accessible informational products helpful in building positive practical solutions to behavioral challenges of people with mental retardation and/or autism. *Education and Training in Mental Retardation and Developmental Disabilities, 36*, 441–456.
- Schaffer v. Weast, 546 U.S. 49 (2005).
- Sudsawad, P. (2007, August). *Knowledge translation: Introduction to models, strategies, and measures*. Austin, TX: Southwest Educational Development Laboratory, National Center for Dissemination of Disability Research.
- Turnbull, A. P., Turnbull, H. R., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust* (5th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.
- Turnbull, H. R., Stowe, M. J., & Huerta, N. E. (2007). *Free appropriate public education: Law and children with disabilities*. Denver, CO: Love.
- Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). *After high school: A first look at the post school experiences of youth with disabilities*. Menlo Park, CA: SRI International.
- Whitehurst, G. J. (2003, April). *The institute of education sciences: New wine, new bottles*. Paper presented at the Annual Meeting of the American Educational Research Association, Chicago, IL.
- Winkelman v. Parma City School District, 550 U.S. 516 (2007).
- Ann Turnbull** (CEC KS Federation), Distinguished Professor, Department of Special Education, The University of Kansas, Lawrence. **Nina Zuna** (CEC TX Federation), Distinguished Professor, The Meadows Center for Preventing Educational Risk, Department of Special Education, University of Texas at Austin. **Joo Young Hong** (CEC KS Federation), Doctoral Student and Research Assistant; **Xiaoyi Hu** (CEC KS Federation), Doctoral Student and Research Assistant; **Kathleen Kyzar** (CEC KS Federation), Doctoral Student and Research Assistant; **Shea Obremski** (CEC KS Federation), Doctoral Student and Research Assistant; **Jean Ann Summers** (CEC KS Federation), Research Professor; and **Rud Turnbull** (CEC KS Federation), Distinguished Professor, Department of Special Education, The University of Kansas, Lawrence. **Matt Stowe** (CEC MO Federation), Administrative Director, Hope Center for Neurological Disorders, Department of Neurology, Washington University School of Medicine, St. Louis, Missouri.

Address correspondence to Ann Turnbull, The University of Kansas, Lawrence, KS 66045 (e-mail: [aturnbull@ku.edu](mailto:aturnbull@ku.edu)).

TEACHING Exceptional Children, Vol. 42, No. 3, pp. 42–53.

Copyright 2010 CEC.

Copyright of Teaching Exceptional Children is the property of Council for Exceptional Children and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.