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### Critical Nature of Treatment and Intervention Selection

There are a number of treatment and intervention options available for people with intellectual disabilities. These range from evidence-based treatments (as described in Chap. 28), such as those derived from the principles of applied behavior analysis (ABA), to unsupported treatments (as described in this chapter), such as complementary and alternative medicine (CAM) treatments. On balance, it can be argued that interventions with empirical support represent better options for the majority of individuals with intellectual disabilities compared to interventions without such support.

Families, schools, and governments have finite financial resources, and the economic burden of intellectual disabilities can be significant. For example, the cost of supporting one individual with comorbid intellectual disability and autism spectrum disorder (ASD) over the life span has been estimated to cost US\$2.4 million in the United States (US) and US\$2.2 million in the United Kingdom (UK) (Buescher, Cidav, Knapp, & Mandell, 2014). In comparison, in both the US

and the UK, the estimated cost of supporting an individual with ASD but without intellectual disability over the life span was US\$1.4 million (Buescher et al., 2014). In Australia, the total government expenditure on services for people with intellectual disabilities has been estimated at A\$3.361 billion each year (Doran et al., 2012).

In addition to financial costs, individuals with intellectual disabilities, family members of these individuals, and professionals who work with them have limited time, resources, and energy to devote to implementing treatments and interventions. Given the finite nature of these resources, it is critical that money, time, and energy are used effectively. While there is no one treatment or intervention that is guaranteed to be effective for all individuals with intellectual disabilities, there are clearly treatments and interventions that are evidence-based and others that are not supported by empirical evidence (Bowen & Snow, 2017; Courtade, Test, & Cook, 2015; West, McCollow, Kidwell, Umbarger, & Cote, 2013). An investment in the use of an evidence-based treatment or intervention is an investment in a treatment or intervention that is more likely to be effective. In contrast, if parents or professionals choose to invest in treatments or interventions that lack empirical support, not only are these treatments/interventions less likely to work, but there is also an opportunity cost. Time, energy, and resources will be devoted to the treatment or intervention that is less likely to be effective, and as a result

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this may lead to the parent or professional forgoing the use of evidence-based treatments and interventions.

Parents of individuals with intellectual disabilities and/or ASD and professionals working with individuals with these diagnoses are typically using a range of treatments and interventions including those that are unsupported by research evidence and/or those that are controversial (Burns & Ysseldyke, 2009; Carter, Stephenson, & Strnadová, 2011; Goin-Kochel, Mackintosh, & Myers, 2009; Haessler et al., 2016; Matson & Neal, 2009; Matson & Williams, 2015). It is therefore important to consider the range of factors related to treatment and intervention decisions made by both parents and professionals in order to understand how these decisions are made and how better decision-making may be supported in the future.

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## Factors Related to Treatment and Intervention Decisions

In recent years the decision-making, particularly of parents, regarding treatment and intervention use has become a research area of interest. As a result, an increasing number of research studies have been published in this area. It is important to note that most of the published research in this area is related to decision-making regarding treatments and interventions for individuals with ASD, but comorbidity of intellectual disabilities and ASD is common (as addressed in Chap. 49). This research will be presented along with research related to decision-making for treatments and interventions for intellectual disabilities and other specific diagnoses that are characterized by intellectual disabilities, such as Fragile X and Down syndrome.

## Decision-Making of Parents

### Introduction

Factors that are related to the decisions of parents regarding intervention use have been explored in the research literature. These include both factors

that parents have explicitly identified as influencing their decision-making, known as *declared decision-making factors*, and other underlying factors that may influence parent decision-making but that parents may not necessarily be aware of, known as *implicit decision-making factors* (Carlon, Carter, & Stephenson, 2013; Wilson, Hamilton, Whelan, & Pilkington, 2018). *Declared decision-making factors* include factors such as recommendations from others, research evidence, and pragmatic considerations, while *implicit decision-making factors* include parent and child factors such as age, gender, and time since diagnosis (Carlon et al., 2013; Wilson et al., 2018).

### Declared Decision-Making Factors

In the research literature, a range of factors have been explicitly identified by parents of individuals with intellectual disabilities, ASD, or both, as influencing their treatment and intervention decision-making. It should be acknowledged that most of this literature relates to the decision-making of parents of children with ASD, which is suggestive for parents of children with intellectual disabilities (e.g., Bowker, D'Angelo, Hicks, & Wells, 2011; Dinora & Bogenschutz, 2018; Tzanakaki et al., 2012). However, where studies have addressed the decision-making of parents of children with intellectual disabilities, these have been included (e.g., Foran & Sweeney, 2010; Prussing, Sobo, Walker, & Kurtin, 2005). In addition, some studies addressed both the decision-making of parents of children with intellectual disabilities and of parents of children with ASD (e.g., Robert, Leblanc, & Boyer, 2015; Wodehouse & McGill, 2009); and some addressed the decision-making of parents of children with ASD including some children with comorbid intellectual disability diagnoses (e.g., Hanson et al., 2007; Shyu, Tsai, & Tsai, 2010). Declared decision-making factors that have been frequently examined in the literature are presented below.

### Advice and Recommendations

Parents of children with intellectual disabilities and of children with ASD receive information

and advice about treatments and interventions available from many sources. These may include other parents, medical doctors, the Internet, teachers or educators, friends/relatives, autism organizations/associations, popular media, books/authors on autism, therapists (including speech therapists, occupational therapists, behavior analysts, audiologists, and physical therapists), psychologists, disability support groups and newsletters, research literature, childcare providers, and diagnostic services (Carlson et al., 2013; Carlson, Stephenson, & Carter, 2015; Dinora, Bogenschutz, & Lynch, 2017; Prussing et al., 2005).

A common theme in the literature related to the type of information offered to parents by professionals, particularly around the time of their child's diagnosis, is that, while some professionals provide useful advice and guidance, this is not always the case. The information provided can be limited and professionals may not always provide advice that parents consider to be useful in their decision-making (see Carlson, Stephenson, & Carter, 2015; Dinora & Bogenschutz, 2018; Sansosti, Lavik, & Sansosti, 2012; Tzanakaki et al., 2012; Wodehouse & McGill, 2009). Parents can be expected to make complex decisions about treatment and intervention use that can leave them feeling unsupported:

"... several families indicated that they 'were getting the runaround from professionals and schools... no recommendations... no road map.'" (Sansosti et al., 2012, p. 88)

"i am using no treatments now, since diagnosis ive been left alone, its like they say shes this, now get on with it." (Mackintosh, Goin-Kochel, & Myers, 2012, p. 57)

"When a mother of a 4-year-old was asked what advice she would give a pediatrician about how to work with families of children with autism, she said, "Listen. I want them to listen to me. Don't be afraid to offer advice. It is okay. I need it. Don't worry about offending me. Honestly. Be honest with me. Don't give me some run-around because I will know if you are just telling me what I want to hear. Be real.'" (Levy et al., 2016, p. 575)

"My biggest gripe about when you get a diagnosis is that you're a parent — you're not a doctor,

you're not a speech therapist, you're not an occupational therapist, but you're given a pack and given the FaHCSIA money<sup>1</sup> and told to make the decision as to how you are going to treat your own child. It all depends on, possibly it all depends on, the first person you see and their opinion that they give you, or you just educate yourself and then try to figure out what your child needs — but it's a bit like a doctor saying, 'You've got cancer. How would you like to treat it?'" (Carlson, Stephenson, & Carter, 2015, p. 122)

Most of the research related to advice and recommendations is limited to the examination of the sources of advice reported to be used by parents, and some qualitative examination of the parent perceived usefulness of such advice. Some researchers, however, have also examined the weight of importance that parents place on recommendations from different sources when making treatment and intervention decisions. Two recent survey studies conducted in the US have provided some insight into the relative level of influence that different sources of information had on parent decision-making regarding ASD interventions and treatments. Dinora et al. (2017) reported that the parents of children with ASD who participated in their study rated developmental pediatricians, their spouse, school staff, speech language pathologists, and primary care physicians as having the most influence (moderate to high influence) on their intervention decisions. Television shows, magazines, social media, and other people were rated as having the least influence (Dinora et al., 2017). Participants in Deyro, Simon, and Guay (2016) were asked to rank six information sources (professional referral, general media, other parents with a child or children with ASD, autism organizations, books, and scientific journals) based on the level of influence on treatment and intervention deci-

<sup>1</sup>In Australia, the Federal Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) provided eligible families of children under 7 years of age with a confirmed ASD diagnosis up to A\$12,000 over 2 years to fund early intervention services provided by a range of approved providers. Parents were provided with information (but not advice) about these services from *Autism Advisors*. The parents were required to choose how to spend these funds.

sions. The source ranked as most influential by the greatest number of participants was professional referrals (48.5%), followed by other parents (20%) and scientific journals (10%). A total of 34.3% of participants indicated that the general media was the least influential source, followed by scientific journals (24.4%), then books, and other parents (5% each).

In Australia, Carlon, Carter, and Stephenson (2015) asked parents of preschoolers with ASD to rate the level of importance they placed on a range of factors (including advice from different sources) when making the decision to use the intervention they nominated as the most important intervention currently being used with their child. On a scale of 1–5 (1 = very unimportant, 5 = very important), advice from therapists received a mean rating of 4.5, advice from teachers or educators 4.1, advice from medical doctors 4.0, advice from other parents 3.9, and advice from friends or relatives 3.2. Consistent with the findings of Deyro et al. (2016), this indicates that parents placed a greater weight on recommendations received from professionals than those received from other sources (Carlon, Carter, & Stephenson, 2015).

Nevertheless, research related to the weight placed by parents on different sources of advice is limited. The findings of Carlon, Carter, and Stephenson (2015), Deyro et al. (2016), and Dinora et al. (2017) indicate that the sources of information that are most frequently addressed in the research literature may not necessarily be the most influential on parent decision-making. For example, other parents are most frequently identified as sources of advice in the literature related to parent decision-making regarding treatments and interventions for ASD (Carlon et al., 2013), yet in Carlon, Carter, and Stephenson (2015), Deyro et al. (2016), and Dinora et al. (2017), parents indicated that other parents had less influence on their decision-making than other sources of advice (such as professionals).

### Child Factors

**Individual needs.** Unsurprisingly, the individual needs or characteristics of the child are frequently reported in the literature as factors considered in

decision-making for parents of children with intellectual disabilities and of children with ASD (Carlon et al., 2013; Edwards, Brebner, McCormack, & MacDougall, 2018; Finke, Drager, & Serpentine, 2015; Prussing et al., 2005; Robert et al., 2015). There is also some evidence that parents may place considerable weight on their child's individual needs in their decision-making. In the Carlon, Carter, and Stephenson (2015) survey of Australian parents of preschoolers with ASD, the participants were asked to indicate the level of importance that a range of factors had on both their decisions to use a nominated intervention and to reject a nominated intervention. All participants indicated that the child's individual needs were important in the decision to use the intervention nominated as the most important intervention currently used with their child. It was also the factor with the highest mean importance ratings in both the decisions to use and to reject the nominated interventions.

**Age.** The age of the child appears to be a factor that is considered by parents in some treatment and intervention decisions, but it has not been as widely examined as an explicitly stated factor in decision-making as other child factors (Carlon et al., 2013; Wilson et al., 2018). However, the implicit relationship between child age and treatment/intervention decisions has been extensively examined and is discussed in section "Declared Decision-Making Factors".

**Side effects or adverse effects.** Parents of children with intellectual disabilities and of children with ASD have reported side effects or adverse effects of treatments as reasons for discontinuing treatments (Bowker et al., 2011; Prussing et al., 2005). In addition, concerns about the safety and possible side effects of medications have also led to parents rejecting the use of conventional medications and choosing to use CAM treatments as alternatives (Bilgic et al., 2013; Hanson et al., 2007; Wong, 2009). However, it appears that not all parents view CAM treatments as a safe alternative. For example, Prussing et al. (2005) reported that some parents decided not to try CAM treatments with their children with Down syndrome due to concerns regarding efficacy and safety. Nonetheless,

although the specific treatments considered by parents as safer or riskier options may vary from parent to parent, the evidence suggests that parents may consider the safety of treatments in terms of actual or possible side effects or adverse effects when deciding whether to commence and/or discontinue the use of these treatments.

**Perceived enjoyment.** Whether or not the parent believed the child would enjoy the intervention or treatment, including consideration of possible resistance to the intervention or treatment, has been reported to be considered by parents across several studies (e.g., Carlon, Carter, & Stephenson, 2015; Christon, Mackintosh, & Myers, 2010; Shyu et al., 2010). These have been limited to the ASD population, including one study with some participants with comorbid intellectual disability diagnoses.

**Perceived child progress.** Frequently in the literature addressing decision-making for ASD treatments and interventions, parents have indicated that their perception of their child's progress has influenced their decision to either continue using (Edwards et al., 2018) or to discontinue the use of a treatment/intervention (Bowker et al., 2011; Christon et al., 2010; Edwards et al., 2018). While some parents discontinued treatments and interventions due to a perceived lack of progress, others did so because they believed that the treatment or intervention was no longer required, either because the child's skills had progressed to a level where the treatment/intervention was no longer necessary and/or because the child had completed the treatment/intervention (Bowker et al., 2011; Christon et al., 2010; Finke et al., 2015).

### **Emotion-Based Factors**

The influence of emotion-based factors has mostly been examined in qualitative research regarding parent decision-making for both interventions for ASD and for intellectual disabilities. A sense of hope, both for improvement (Carlon, Carter, & Stephenson, 2015; Finke et al., 2015; Tzanakaki et al., 2012) and for a cure (Carlon, Carter, & Stephenson, 2015; Finke et al., 2015), has been identified by parents as a consideration in treatment and intervention decision-making.

Parents have also reported following their own intuition or "gut feelings" when selecting interventions (Carlon, Carter, & Stephenson, 2015; Prussing et al., 2005). Participants in Carlon, Carter, and Stephenson (2015) rated the importance of factors in their decision to use a nominated intervention. They ranked emotion-based factors significantly higher in importance than advice/recommendations. However, these parents placed significantly more weight on service characteristics, research evidence, and child factors than on emotion-based factors. In contrast, when asked about factors influencing decisions to reject a nominated intervention, emotion-based factors were ranked significantly higher than both pragmatic factors, research evidence, and advice/recommendations. For the decision to reject the nominated intervention, emotion-based factors received the highest mean importance ranking of all of the examined categories of factors.

### **Pragmatic Factors**

Unsurprisingly, there are a range of pragmatic considerations that parents of children with intellectual disabilities and of children with ASD take into account when making decisions about treatment and intervention use. One of the first considerations of parents may be whether a specific treatment or intervention is available and accessible to the family. The availability and accessibility of the treatment/intervention have been reported frequently as decision-making factors in the literature (see Carlon et al., 2013; Dinora et al., 2017; Edwards et al., 2018). Some interventions can be restricted to specific diagnostic criteria and/or only offered to individuals with a specific level of functioning, which in turn can limit intervention options (Foran & Sweeney, 2010; Robert et al., 2015).

Related to availability, parents commonly report that there are waiting lists for services, particularly those that are publicly funded (Dinora et al., 2017; Foran & Sweeney, 2010; Robert et al., 2015; Sansosti et al., 2012; Valentine, 2010). In addition to access to intervention services provided as part of public health or education systems, access (or lack thereof) to

government funding support and/or to insurance cover has been reported to influence parent treatment and intervention decision-making in several studies (Dinora et al., 2017; Edwards et al., 2018; Grant, Rodger, & Hoffmann, 2016; Mackintosh et al., 2012; Shepherd, Csako, Landon, Goedeke, & Ty, 2018; Valentine, Rajkovic, Dinning, & Thompson, 2010). The cost of treatments and interventions, whether related to access to external funding or not, is a logical consideration for parents. As such, it has been reported across several studies (Carlon et al., 2013; Carlon, Carter, & Stephenson, 2015; Edwards et al., 2018; Robert et al., 2015; Sansosti et al., 2012; Shepherd et al., 2018).

Other pragmatic considerations include the convenience to or impact on the family (Edwards et al., 2018; Rajkovic, Thompson, & Valentine, 2010). Some parents have chosen to discontinue interventions or not implement interventions suggested by professionals because they did not suit their family (Robert et al., 2015). This can be related to a failure to *fit the schedule* of the child and family, and/or to the treatment or intervention being perceived as inconvenient by the family (Rajkovic et al., 2010; Robert et al., 2015; Yingling, Hock, Cohen, & McCaslin, 2017). Time constraints were also reported to be related to intervention decisions across several studies (Carlon et al., 2013).

### Research Evidence

Mixed results have been reported regarding the impact of research evidence on parent decision-making regarding treatment and intervention use for both intellectual disabilities and ASD. Although research has been reported to be considered by parents in a number of studies (Carlon, Carter, & Stephenson, 2015, 2017; Deyro et al., 2016; Dinora et al., 2017; Hanson et al., 2007; Prussing et al., 2005; Valentine, 2010), parents continue to use interventions that are not supported by research evidence (Goin-Kochel et al., 2009; Matson & Williams, 2015). In some studies where participants were directly asked about consideration of research evidence, this term was not defined for parents (e.g., Carlon, Carter, & Stephenson, 2015), so even though the

parents indicated that research was important in their decision-making, their interpretation of research evidence may not have been the same as the researchers' interpretation of this term. This is possibly because parents may interpret *research evidence* to mean their own efforts to find information about treatments and interventions or anecdotal reports of treatment/intervention effectiveness, as opposed to the findings of empirical studies.

There is limited research addressing parents' ratings of the empirical support for treatments and interventions. Deyro et al. (2016) asked parents of children with ASD in the US to rate the effectiveness of and level of research support for 26 treatments/interventions for ASD. The authors compared these parent ratings to the ratings provided by the National Autism Centre in the National Standards Report as a result of a comprehensive review of the research support for treatments and interventions for ASD (excluding medication; Deyro et al., 2016). The ratings of parents corresponded with the ratings provided by the National Autism Centre for only 9 of the 26 treatments/interventions. In addition, for most of the treatments/interventions rated, parent ratings of research evidence did not correlate with their ratings of the effectiveness of the treatments/interventions (Deyro et al., 2016). Carlon et al. (2017) collected similar data from Australian parents in a pilot study of a parent education package providing information about evidence-based practice, guidelines for selecting interventions, and guided access to two websites that provided information about the scientific efficacy of a range of interventions for ASD. They found that even after the guided access to the websites, parents' ratings of research evidence did not necessarily correspond with the ratings provided on the websites. Ratings of the research support for interventions were positively correlated with the participants' current use of and desire to use interventions, indicating that the participants tended to rate interventions that they were currently using and those that they had a strong desire to use as having strong research support, regardless of the information about research efficacy provided on the websites (Carlon et al., 2017).

### **Intervention/Treatment and Service Characteristics**

Characteristics of the treatment/intervention along with those of service providers delivering specific interventions or treatments have also been reported to be considered by parents of children with intellectual disabilities and with ASD in their decision-making. Intervention characteristics considered have included whether or not the intervention was a diagnosis-specific intervention or more general in nature (Carlson, Carter, & Stephenson, 2015) and whether it would be compatible with other interventions/treatments already being used with the child (Rajkovic et al., 2010; Valentine et al., 2010). In addition, there is some evidence that parents may also consider whether the claims of the proponents of the intervention/treatment are feasible and/or if they fit with the parent's beliefs about the etiology of their child's condition (Bilgic et al., 2013; Prussing et al. 2005).

The characteristics of the staff, including staff experience (Carlson, Carter, & Stephenson, 2015), whether they appeared to be professional (Carlson, Carter, & Stephenson, 2015), and the parent's impressions of their intentions and whether they *fit* with the child and family (Dinora et al., 2017), are also reported to affect parental decision-making. As with the other factors discussed above, there is limited research addressing the weight of importance that parents place on these characteristics in comparison to other factors when making treatment and intervention decisions. Dinora et al. (2017) reported that the fit of the provider with the parent and child was the strongest influence on parent decision-making about ASD treatments and interventions for their US sample. In addition, high importance was placed on staff characteristics by Australian parents of preschoolers with ASD in the survey conducted by Carlson, Carter, and Stephenson (2015).

### **Implicit Decision-Making Factors**

The factors described in the section above were those that were explicitly identified by parents as related to their treatment and intervention decision-making. There are other factors that have been examined by researchers because they

have the potential to influence treatment and intervention decisions. These implicit, underlying factors are factors that parents do not explicitly declare and of which they may not be consciously aware. By their nature, implicit factors have tended to be examined in studies using correlational approaches. These data provide an indication of the relative impact of the possible implicit factors relative to others addressed in each study.

It should also be noted that researchers have used available datasets such as health insurance claim data (e.g., Chang, Lin, Tung, Chiang, & Hsu, 2014), service providers' existing records (e.g., Olsson, Elgmark Andersson, Granlund, & Huus, 2017; Paton et al., 2011), and health record databases (e.g., Osunsanmi & Turk, 2016) to examine the relationships between treatments/interventions used by individuals with intellectual disabilities and factors such as gender, age, school class placement (specialized or mainstream), comorbid diagnoses, presence of problem behavior, and living circumstances. The person(s) responsible for deciding whether to use each of the treatments and interventions in these studies is unknown. Decisions may have been made by medical staff, educators, the individual with an intellectual disability, or family members, for example. While these studies provide some insight into the range of factors that may be associated with the use of specific treatments and interventions for intellectual disabilities and/or ASD, they cannot provide unambiguous insight into the decision-making of parents or other caregivers when the decision-maker is unknown. For this reason, the research examined in this section is limited to studies in which data were collected directly from the parent(s), including secondary analysis of such data. Similarly, other research addressing the relationships between implicit factors and healthcare service use and/or expenditure on healthcare for children with intellectual disabilities (e.g., Adams et al., 2016; Lin et al., 2013; Wilkins et al., 2010) has not been considered here because it does not provide insight into the specific treatments/interventions employed by these medical and allied health service providers and related parent decision-making.

## Implicit Factors

In recent years researchers have examined relationships between a range of possible implicit decision-making factors and parent treatment/intervention decisions for intellectual disabilities (e.g., Sheehan, Kimona, Giles, Cooper, & Hassiotis, 2018; Zablotsky et al., 2015), Fragile X (e.g., Bailey Jr. et al., 2012; Laxman et al., 2018; Martin et al., 2013), and ASD (e.g., Denne, Hastings, & Hughes, 2017; Irvin, McBee, Boyd, Hume, & Odom, 2012; Mire, Hughes, Manis, & Goin-Kochel, 2018; Salomone, Charman, McConachie, & Warreyn, 2015; Zablotsky et al., 2015). The possible implicit factors examined can be broadly classified as either child-related factors, parent-related factors, or family-related factors (Wilson et al., 2018).

Although age was a factor that was explicitly stated as influencing parent decision-making in a number of studies, it has also been widely examined, using correlational approaches, in cases where the parents did not explicitly state that the child's age was a factor that they considered in their decision-making (Denne et al., 2017; Goin-Kochel, Myers, & Mackintosh, 2007; Laxman et al., 2018; Lindly, Thorburn, Heisler, Reyes, & Zuckerman, 2017; Martin et al., 2013; Miller, Schreck, Mulick, & Butter, 2012; Mire, Gealy, Kubiszyn, BurrIDGE, & Goin-Kochel, 2017; Mire, Raff, Brewton, & Goin-Kochel, 2015; Owen-Smith et al., 2015; Salomone et al., 2015, 2016; Sheehan et al., 2018; Shepherd et al., 2018; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Witwer & Lecavalier, 2005; Wong & Smith, 2006). Other child factors that have been examined include the gender of the child (Laxman et al., 2018; Lindly et al., 2017; Martin et al., 2013; Owen-Smith et al., 2015; Patten, Baranek, Watson, & Schultz, 2013; Salomone et al., 2015, 2016; Sheehan et al., 2018; Shepherd et al., 2018; Witwer & Lecavalier, 2005; Wong & Smith, 2006), the type of diagnosis and/or perceived severity of symptoms associated with diagnosis (Bailey Jr. et al., 2012; Hall & Riccio, 2012; Laxman et al., 2018; Lindly et al., 2017; Mire et al., 2017; Owen-Smith et al., 2015; Patten et al., 2013; Salomone et al., 2016; Sheehan et al., 2018; Thomas et al., 2007; Witwer &

Lecavalier, 2005; Zablotsky et al., 2015), time since diagnosis (Miller et al., 2012; Salomone et al., 2016; Zuckerman, Lindly, & Chavez, 2017), comorbid conditions (Bailey Jr. et al., 2012; Laxman et al., 2018; Martin et al., 2013; Sheehan et al., 2018; Zablotsky et al., 2015), age at diagnosis (Lindly et al., 2017; Zuckerman et al., 2017), and presence of challenging behavior (Laxman et al., 2018; Sheehan et al., 2018).

Possible relationships between treatment/intervention decisions and family-related factors have also been examined in the literature. Family income or socioeconomic status has been examined across several studies, and the findings have been mixed (Bailey Jr. et al., 2012; Denne et al., 2017; Irvin et al., 2012; Laxman et al., 2018; Miller et al., 2012; Mire et al., 2017; Owen-Smith et al., 2015; Patten et al., 2013; Thomas et al., 2007); family size was examined in only a small number of studies (Lindly et al., 2017; Shepherd et al., 2018), as was health insurance coverage (Lindly et al., 2017; Thomas et al., 2007; Zablotsky et al., 2015). In comparison, the geographic location of the family was relatively more widely examined (Lindly et al., 2017; Mire et al., 2018; Salomone et al., 2015, 2016; Thomas et al., 2007). Examination of the relationship between ethnic background and treatment/intervention use has mainly occurred in the North American context, where the results have been mixed (Hall & Riccio, 2012; Irvin et al., 2012; Lindly et al., 2017; Owen-Smith et al., 2015; Patten et al., 2013; Reyes et al., 2018; Thomas et al., 2007). Other parent-specific factors examined have included the parents' age (Miller et al., 2012; Shepherd et al., 2018; Wong & Smith, 2006), parent education levels (Denne et al., 2017; Hall & Riccio, 2012; Lindly et al., 2017; Miller et al., 2012; Mire et al., 2017; Owen-Smith et al., 2015; Patten et al., 2013; Salomone et al., 2015, 2016; Shepherd et al., 2018; Thomas et al., 2007; Wong & Smith, 2006), marital status (Hall & Riccio, 2012; Owen-Smith et al., 2015), parents' beliefs or perceptions about their child's disability (including etiology; Dardennes et al., 2011; Lindly et al., 2017; Mire et al., 2017; Reyes et al., 2018), and parent/caregiver stress (Irvin et al., 2012; Thomas et al., 2007).



In general, when relationships between implicit factors and intervention/treatment use have been examined, few significant relationships have been found. Where significant relationships have been found, these findings have not necessarily been replicated in other studies. For example, some beliefs about ASD have correlated with the use of certain treatments and interventions, but the specific beliefs and treatments/interventions these are associated with have varied from study to study (see Dardennes et al., 2011; Lindly et al., 2017; Mire et al., 2017; Reyes et al., 2018). This is possibly a reflection of the idiosyncratic nature of parent decision-making.

Nevertheless, a few consistent findings have emerged. The relationship between the child's gender and treatment/intervention use was examined across a number of studies and was not found to be associated with the use of a particular treatment or intervention in the majority of studies in which it was examined (See Laxman et al., 2018; Lindly et al., 2017; Wilson et al., 2018). Another consistent finding that has emerged across the studies is that when parent education levels and CAM use have been examined, those who are more highly educated have been found to be more likely to use CAM interventions (Hall & Riccio, 2012; Owen-Smith et al., 2015; Patten et al., 2013; Salomone et al., 2015; Wong & Smith, 2006).

### Summary

The majority of research related to parent decision-making regarding treatments and interventions has been conducted with parents of preschoolers and school-age children with ASD. Factors influencing parent decision-making include both those explicitly declared by parents as influencing their decisions and other implicit underlying factors that have been examined using correlational research (Carlson et al., 2013; Wilson et al., 2018). The most frequently examined declared decision-making factors include advice or recommendations from others, child factors (such as individual child characteristics), and pragmatic considerations (such as cost, funding, and accessibility). There is limited research

related to the weight or level of importance that parents place on the different factors as they make decisions, but the evidence to date indicates that multiple factors are considered by parents as they make decisions and that those factors that are most frequently reported in the research are not necessarily those that have the most influence on parent decision-making.

A vast range of implicit underlying parent, child, and family factors may also be related to parent decision-making. These potential relationships have been examined using correlational research. Few significant relationships have been found in studies examining implicit factors, and where relationships have been found these have not tended to be replicated across studies. There are two consistent findings that have emerged: (1) child gender has not appeared to be related to treatment and intervention decisions; and (2) higher parent education levels have tended to be correlated with the use of CAM treatments. With these two exceptions, overall, the findings in this area have been inconsistent, and this may be reflective of the complex interplay between a range of competing declared decision-making factors and idiosyncratic implicit child, parent, and family factors.

## Decision-Making of Teachers

### Introduction

Students with intellectual disabilities may be educated in a range of contexts, including inclusive settings where a regular class teacher is responsible for their education through to self-contained settings with a special educator. Teacher decision-making in any setting is complex, and using theories of natural decision-making may be best seen as a process for solving problems, with the solutions constrained by a range of teacher and contextual factors, including values, attitudes, beliefs, resourcing, and system demands (Robinson, 1998; Robinson & Donald, 2015). Conventional theories of decision-making assume that once teachers know about effective interventions, they will make a rational decision to use them and that they will monitor the impact

on their students and retain effective practices. The well-documented research-to-practice gap in special education indicates that this does not happen (Gersten, Vaughn, Deshler, & Schiller, 1997). A first step in understanding teacher decision-making in natural contexts is to identify factors that may influence teacher decision-making and the characteristics of teachers that determine which factors are considered. The factors influencing decisions may be conflicting, and an understanding of teacher decision-making requires an understanding of how teachers resolve those conflicts and decide on a course of action (Robinson, 1998).

### **Evidence-Based Practice**

Although the ideal of researchers and the thrust of recent policies such as No Child Left Behind in the US would be that in the main special educators and teachers in segregated and inclusive settings would choose to use evidence-based interventions with research evidence to support them, the research-to-practice gap is widely recognized as a problem within special education (Greenway, McCollow, Hudson, Peck, & Davis, 2013; McLeskey & Billingsley, 2008). Gersten et al. (1997) suggested principles that would support uptake and use of effective practices. Interventions must be feasible and practical for classrooms (the reality principle) and only involve a reasonable amount of change to teacher practices. The changes must be linked to student outcomes. Teachers need the opportunity to practice an intervention with feedback and to link the concepts underpinning research to classroom realities. Simply knowing about an intervention is not sufficient for a teacher to decide to use it.

In the literature addressing the research-to-practice gap, researchers have suggested a range of reasons why teachers do not use evidence-based practices, but there is little investigation of teacher perspectives on the use of research. For example, Cook and Cook (2004), in writing about the education of students with learning disabilities, suggest that within natural decision-making, teachers largely ignore research findings as a factor. They suggest this because teacher preparation does not present research well, there are

difficulties in the translation of research to practice, and school cultures may not value research. Similarly, Hornby, Gable, and Evans (2013) summarized the reasons generally why special education teachers are resistant to evidence-based practice as distrust of educational research and interventions described as best practice, a preference for guidance from experienced teachers, a preference for existing practices and lack of appropriate education, and professional development. McLeskey and Billingsley (2008) also noted the two factors of inadequate teacher education about research and the nature of research itself but added other factors related to teaching contexts, such as large caseloads and lack of support that may not always support best practices.

Guckert, Mastropieri, and Scruggs (2016) interviewed highly qualified special educators teaching students with learning difficulties, autism, and severe disabilities and examined their documentation to determine their perceptions and use of evidence-based practices. They found that although all teachers believed they were using evidence-based practices, there was a wide range in awareness of evidence-based practice and research. The aware teachers trusted research and could explicitly state that a practice was evidence-based, used it, discussed it with others, and relied on it. The partially aware group did not provide specific descriptions of evidence-based practices and was hesitant about sharing research evidence with colleagues, sometimes implemented and occasionally relied on evidence-based practice. The unaware group was skeptical about using evidence-based practices and reported it was not common to discuss the source of strategies chosen with colleagues and that they sometimes implemented evidence-based practices but rarely relied on them. Aware teachers reported personalizing research in explicit and effective ways, while the partially aware teachers may not have always implemented strategies effectively and described barriers such as time demands. The unaware teachers were less aware of the sources and components of strategies and were more likely to make unsuitable adaptations.

## Decision-Making and Intellectual Disabilities

There appears to be little research directly and specifically examining the decision-making of teachers in regard to students with intellectual disabilities (Greenway et al., 2013), although it appears to be an area of emerging interest, particularly in relation to decision-making for students with severe intellectual disabilities. Greenway et al. (2013) offer one of the few studies specifically investigating teacher decision-making for students with intellectual and developmental disabilities. They interviewed nine teachers about their experiences and perceptions regarding evidence-based practices. Like the participants in Guckert et al. (2016), they had varied understandings of evidence-based practices, but they also discussed their access to resources, interactions with other people and organizations, and the interactions between these. Some teachers valued the autonomy they had as special educators but noted it came with less accountability, less supervision, and less collaboration. They reported that in this context, district policies about evidence-based practices were absent or not seen by others as relevant. Teachers wanted evidence-based resources to be made available, such as curricula and more access to professional learning, consultancy, and research literature, so it appears access to sources of reliable information may limit the use of some practices.

Andzik, Chung, Doneski-Nicol, and Dollarhide (2017) interviewed teachers of students with intellectual or developmental disabilities about the factors affecting decisions to use augmentative and alternative communication (AAC). Teachers described barriers to implementing AAC which were similar to those reported in earlier studies such as the lack of training in AAC, limited preparation time, and variable support from speech language pathologists and others. These practical factors were seen to limit student access to AAC, as did teacher knowledge of assistive technology.

More specifically, Ruppap, Gaffney, and Dymond (2015) investigated teacher decision-making in respect to literacy for secondary

students with severe disabilities most of whom had intellectual disabilities. They identified four major factors that contributed to teacher decision-making about literacy. Teacher beliefs concerning the student, learning, and teaching determined the degree of individualization of lessons. Their expectations of the student influenced the goals they set, with those teachers who held lower expectations of their students being more likely to have set restrictive goals. Teachers with high self-efficacy were less likely to seek expert help or professional learning. In addition, Ruppap et al. (2015) identified a range of contextual factors which interacted with the teacher factors including staffing, in-class assistance and teaching materials available, level of support from colleagues, administrators and policies, philosophies about curriculum, personal and professional experiences, and professional development.

This research then, mostly recent, which describes specifically teachers of students with intellectual disabilities, and mostly those teaching students with severe disability, has identified a range of interacting teacher and contextual factors. Within teacher factors include teacher understanding of evidence-based practices, teacher knowledge, teacher attitudes and beliefs about students and teaching, and teacher self-efficacy. Contextual factors include access to resources and reliable information about evidence-based practices, access to support and collaboration with others, administrative and policy issues, and limited time.

Despite this lack of research directly relevant to students with intellectual disabilities, research on the education of students with disability more generally offers further useful information on factors influencing teacher decision-making. Surveys of special educators explore reported practices in relation to teacher characteristics. In addition, investigations addressing the acceptability of interventions to special and general educators and research, often qualitative, which explores special educator reports of their beliefs, attitudes, and practices and the reasons they give for selecting interventions may all contribute.

### Practices and Teacher Characteristics

Multiple surveys of special education teachers have revealed that although they may use evidence-based practices, it is common for them to also use unproven and disproven practices. Burns and Ysseldyke (2009) surveyed both special education teachers (about a third of whom taught students with intellectual disabilities) and school psychologists in the US and found that some sound interventions, such as direct instruction, were used frequently. However, there was also high frequency of some ineffective interventions; for example, modality instruction was used as frequently as applied behavior analysis (an intervention with strong empirical support). Although they did not directly examine teacher characteristics in relation to reported use, they suggest that factors such as perceived effectiveness, resource demands, alignment with the teacher's own theories, and intrusiveness may be relevant. They also noted that respondents were members of the Council for Exceptional Children and thus may have been more aware of current research and best practices than nonmembers.

Carter et al. (2011) replicated the Burns and Ysseldyke (2009) survey with Australian special educators, and although they found high levels of use of a number of evidence-based practices, such as direct instruction and applied behavior analysis, they also reported moderate-to-high levels of use of a number of interventions with poor research support, such as modality instruction and perceptual motor programs. There were differences in use depending on the nature of students taught, with social skills training used more with students with severe and profound disabilities. There was no correlation between practices used and qualifications in special education, although the sample was drawn from members of the Australian Association of Special Education, who like the Burns and Ysseldyke (2009) sample may have been more aware of current research. A survey of special education teachers in the Czech Republic (Carter, Strnadová, & Stephenson, 2012) revealed a similar pattern, with high frequency of use reported for the evidence-based practices, applied behavior analysis, and direct instruction but also frequent use of practices

without strong empirical support, such as perceptual motor training. Here teachers of students with severe and profound disability generally reported more use of both evidence-based and non-evidence-based strategies, and use of perceptual motor and psycholinguistic training was associated with higher levels of special education training.

Knight, Huber, Kuntz, Carter, and Juarez (2018) surveyed special educators teaching students with intellectual disabilities and/or autism about instructional practices. They found considerable variability in the practices teachers reported that they used but, like previous surveys, found use of both evidence-based strategies such as direct instruction and non-evidence-based interventions such as sensory integration. They also looked at factors that influenced teacher decision-making and found teachers were more likely to use interventions when they had received training or resources related to the intervention in the previous year. Other influences were setting (more use of evidence-based practices in special education classes), caseload, and age of students. The educational level and experience of teachers had little relation to the use of evidence-based practices. The teachers themselves reported that student need, the skills to be taught, and their perceptions of effectiveness of the practice influenced decisions. Decision-making was not generally influenced by research support, expert advocacy, or preservice education, but also recent training and recommendations from other teachers were influential. Similarly, Lawson and Jones (2017) who focused more on minute-to-minute decision-making than intervention selection and who both interviewed and observed teachers found that knowledge of individual students was a factor in all decision-making. Lawson and Jones (2017) also noted consultation with others, training, and mandated programs as influences.

Despite the results from Carter et al. (2011, 2012) and Knight et al. (2018) suggesting that there is little relationship between qualifications in special education and self-reported intervention choices, other research suggests that the nature of teacher qualifications does have an impact on instructional decision-making for

students with disability generally. Teachers with special education qualification get better academic results than those without (Feng & Sass, 2012; Hanushek, Kain, & Rivkin, 2002) which suggests use of more effective strategies. Survey research shows special educators who had completed relevant coursework or professional learning were more likely to report the use of effective practices regarding transition (Morningstar & Benitez, 2013). In a survey of special educators working with students with emotional and behavioral difficulties, Stormont, Reinke, and Herman (2011) found special educators were better able to identify evidence-based and non-evidence-based behavioral interventions and were more confident in their intervention choice than regular educators. Bell, Cihak, and Judge (2010) surveyed student teachers in an alternative special education licensure program and found knowledge and use of assistive technology were strongly related to teacher preparation. Participants in this survey also reported perceptions of barriers to the use of assistive technology which included lack of time, knowledge, and funding.

### Teacher Attitudes and Beliefs

For students with intellectual disabilities who are educated in inclusive settings, there is also little specific research. There is a view that positive attitudes to inclusion are more likely to lead to teachers making decisions to implement effective practices but that teachers are likely to hold more negative attitudes to the inclusion of students with intellectual disabilities (Avramidis & Norwich, 2002). Carlson, Hemmings, Wurf, and Reupert (2012) noted the importance of positive teacher attitudes to inclusion as an element motivating the use of effective practices. They observed and interviewed six teachers, some of whom taught students with intellectual disabilities, described by their principals as exemplary inclusive teachers. All used evidence-based strategies such as feedback, cooperative learning, and elements of direct instruction. The researchers suggested that other evidence-based strategies such as mastery learning were not used because teachers did not know about them. Use of effective

practices was supported by collaboration with families and specialists, good support systems, and appropriate professional learning.

There is little direct evidence linking beliefs and attitudes to intervention decisions, beyond the negative attitudes to inclusion for students with disability. Jordan, Glenn, and McGhie-Richmond (2010) suggested perhaps a quarter of teachers in inclusive settings may believe that a disability is a fixed condition and that students may not benefit from instruction. They make minimal adaptations to instruction and prefer a pullout service model, taking less responsibility for student learning. Similarly, Ruppard, Roberts, and Olson (2018) linked deficit views of disability as fixed and located in the student to different visions of teacher expertise characterized by different teacher behaviors. They interviewed teachers of students with significant disabilities, including intellectual disabilities, their supervisors, and university personnel preparing special educators to explore their visions of expertise. They identified two contrasting visions, strength-based and deficit-based, which were associated with instructional approaches. In the strength-based view, teachers used their knowledge of the student to choose age-appropriate curriculum content and instructional designs, based on student strengths and abilities. In contrast, in a deficit-based vision, the focus was on caregiving and managing behavior rather than instruction. Roberts, Ruppard, and Olson (2018), noting the influence of educational leaders on instructional decision-making, interviewed principals and administrators and found that these leaders “were not able to articulate evidence-based instructional practices” (p. 14). They tended to emphasize caregiving and thus could be considered to hold a deficit view and low expectations of students with severe disabilities and influence teacher practices through these beliefs.

### Acceptability

Research on the acceptability of interventions to teachers also provides some relevant information related to teacher decision-making, although this work has been mostly carried out with teachers of students with learning difficulties or behavioral

disorders and on behavioral intervention (Boardman, Arguelles, Vaughn, Hughes, & Klingner, 2005; Gajria & Salend, 1996). In relation to these teachers, Boardman et al. (2005, p. 168) stated that “Teachers sought instructional practices that were feasible, were appropriate for their students, were accompanied by all necessary materials and professional development support, and could be individualized for multilevel classrooms.” This supported the earlier findings of Gajria and Salend (1996) from a review of research on treatment acceptability for adaptations made for students with disability in mainstream classes. They noted that although choice of adaptations was not solely related to perceived effectiveness, that was a consideration, but for behavioral interventions, the nature of the intervention, the time and resources needed, its theoretical base, and any negative side effects were also considered. For instruction, teachers generally made only superficial changes to lessons rather than adopting new strategies or adjusting curriculum. They preferred interventions that did not need additional resources, did not involve other people, were not time-consuming, and fitted in with their existing practices. Whinnery, Fuchs, and Fuchs (1991) found little difference between special and regular educators of students with mild disabilities in regard to the perceived effectiveness and acceptability of instructional strategies and social behavior interventions addressed in a teacher survey. As in other studies, acceptability was related to perceptions of interventions as effective, but they also noted that teachers may not be aware of some effective interventions.

### **Policies**

Ruppar et al. (2015) noted that policy contexts are one of the factors that might affect teacher beliefs and policies might support or limit the decisions teachers make. The teachers in Greenway et al. (2013) indicated that there were either no relevant district policies for students with intellectual and developmental disabilities or that policies were waived and so policies had little impact on their decision-making. It may be that policies designed for typically developing students are not appropri-

ate for students with disability. Similarly, Boardman et al. (2005) noted that the teachers in their study (teachers of students with learning difficulties or behavior disorders) were often left to make their own decisions, even when districts suggested particular programs. Some studies have explored the impact of district and school policies on teacher behavior. Timberlake (2016) interviewed teachers of students with significant cognitive disabilities and found that they took responsibility for curriculum and instructional decisions, although they did recognize some policy boundaries such as graduation requirements and alternate assessments. Hudson et al. (2016) found special educators expressed varying levels of confidence in curriculum decisions made at higher levels and did not always agree that policy decisions around evidence-based practices for general education were applicable to their students. Lawson and Jones (2017) thought teachers of students with severe intellectual disabilities in Florida, USA, were more subject to policy decisions than those in the UK.

### **Summary**

Overall then, the literature on special educators generally is consonant with research on teachers of students with intellectual disabilities and confirms there are multiple teacher and contextual factors that can interact in various ways to affect teacher decision-making. Table 29.1 presents an overall summary of the factors that have been identified.

Generally, it seems that the principles enunciated by Gersten et al. (1997) 20 years ago to support the use of evidence-based interventions by special educators still hold. Teachers are likely to use interventions that are feasible and practical within the resources available to them (time and materials). They need to be linked to student outcomes so that teachers perceive that the interventions are effective for their students. Where teachers receive education and training in the use of interventions, they are more likely to use them. Finally, teachers who know and understand research and the theories and principles underlying it are more likely to use evidence-based interventions supported by research.

**Table 29.1** Factors influencing teacher decision-making

<i>Within teacher factors</i>
Knowledge and understanding, especially of evidence-based practices
Attitudes to the use of research
Teacher qualifications
Teacher training about specific interventions
Teacher theories and philosophies of learning and teaching
Teacher attitudes and beliefs about students with intellectual disabilities (strength-based or deficit-based)
Teacher perceptions of the effectiveness of an intervention
Teacher perceptions of student need
Teacher knowledge of the student
Teacher self-efficacy
<i>Contextual factors</i>
Resources available, particularly time
Feasibility of interventions
Supports available for an intervention
Side effects of an intervention
Fit with existing practices
Policies at school, district, and system level
Interaction and collaboration with others
Available staffing
Skills and knowledge to be taught
Setting
Level of student disability

### Decision-Making of Other Professionals

Professionals other than teachers are also responsible for making decisions about the treatments and interventions used with individuals with intellectual disabilities. Notably, there has been much less research in this area than in that of parent or teacher decision-making. In particular, there is very little data related to treatment or intervention decision-making in group homes and vocational programs beyond examination of the treatment decisions of intellectual disability nurses (Williams, Roberts, Irvine, & Hastings, 2010) and some comparisons of medication and service use by individuals with intellectual disabilities living with their parents compared with those living in group homes (e.g., Harrington & Kang, 2016; Osunsanmi & Turk, 2016; Tsiouris, Kim,

Brown, Pettinger, & Cohen, 2013). Treatments and interventions for challenging behaviors exhibited by individuals with intellectual disabilities within residential settings have received attention in recent years, with a particular focus on the use of psychotropic and antipsychotic medications (e.g., Bowring, Totsika, Hastings, Toogood, & McMahon, 2017; Doan et al., 2014; O'Dwyer et al., 2017). However, these studies have tended to focus on identifying a range of implicit factors that may be associated with the use of medication without consideration of who was making treatment decisions or the decision-making process undertaken (see Bowring et al., 2017; Doan et al., 2014; Kelly & Su, 2015; O'Dwyer et al., 2017). Thus, this literature provides little insight into how the decisions were made beyond the fact that challenging behavior exhibited by individuals with intellectual disabilities tends to be positively associated with medication use in residential settings (see Bowring et al., 2017; Doan et al., 2014). Other researchers have examined the experiences and practices of residential care staff regarding medication use, including their attitudes toward and understanding of medications (e.g., de Kuyper & van der Putten, 2017; Joos et al., 2014; Lalor & Poulson, 2013). This research has tended to focus on the outcomes of treatment decisions as opposed to how the decisions were initially made and therefore also provides little insight into treatment decision-making.

Although Williams et al. (2010) considered the process of decision-making employed by intellectual disability nurses, it should be noted that other research related to treatment/intervention decisions for adolescents and adults with intellectual disabilities has addressed the outcomes of treatment/intervention decisions as opposed to how those decisions were made (e.g., Harrington & Kang, 2016; Lalor & Poulson, 2013; O'Dwyer et al., 2017; Osunsanmi & Turk, 2016). Most of the research regarding the treatment and intervention decision-making of professionals relates to those working in early intervention, and, similar to the parent decision-making literature, much of this relates to the population of children diagnosed with ASD.

Special education and general teachers may work in early intervention services. The decision-making of teachers working in early intervention is often more collaborative than teachers working in schools. These teachers are often working in teams with other professionals, and best practice guidelines indicate that collaboration with other professionals and, in particular, the family is important (Division for Early Childhood, 2014). Therefore, the decision-making process for those teachers working in early intervention is different to those working in schools. In addition, much of the literature on decision-making of early intervention professionals does not differentiate between the decision-making of teachers and other professionals and paraprofessionals working in early intervention. Hence, it is more appropriate to include research literature related to the decision-making of teachers working in early intervention in the current section than the previous one.

A growing interest has been shown in the decision-making of early intervention professionals in recent years, particularly in relation to ASD interventions. Stahmer, Collings, and Palinkas (2005) conducted focus groups with early intervention providers in the US working with children with ASD regarding the intervention techniques and strategies used. Participants reported using a range of interventions and tended to rate the interventions that they used as being evidence-based, when only about a third of those nominated as evidence-based had research support. Paynter and colleagues have more recently conducted research in Australia examining the knowledge and use of practices by ASD early intervention service providers (Paynter et al., 2017; Paynter & Keen, 2015) and allied health professionals working with individuals with ASD (not necessarily within the early intervention age group; Paynter, Sulek, Luskin-Saxby, Trembath, & Keen, 2018) and the factors related to their decisions to employ different practices. They found that a range of evidence-based, emerging, and unsupported interventions were being used by the early intervention and allied health professionals but that evidence-based practices were being used more than emerging

practices and emerging practices more than unsupported practices (Paynter et al., 2017, 2018; Paynter & Keen, 2015). The intervention practices reported to be used most frequently by the early intervention providers in Paynter et al. (2017) were evidence-based practices, and those used least frequently were unsupported interventions. There were, however, some unsupported interventions that were commonly being used more than once per week, including facilitated communication and multisensory environments. The role/profession of the early interventionist did not appear to be related to the use of these unsupported practices, as there were no significant differences between the use of these interventions by teachers, allied health professionals/social workers, and paraprofessionals (childcare workers). Teachers did report using academic interventions more frequently than allied health professionals/social workers and paraprofessionals (Paynter et al., 2017). This indicates that the professional background of the provider may influence some (but not all) of their intervention decisions.

The use by early intervention and allied health professionals of some interventions that do not have empirical support leads to the question of whether research evidence is a factor that these professionals consider in their decision-making. Stahmer et al. (2005) observed that none of the participants involved in their study reported engaging in professional reading. They concluded that:

“It appears that program marketing, availability of training, provider preference, and external factors such as parent requests influence the use of specific practices more than whether the practice has any evidence of efficacy.” (Stahmer et al., 2005, p. 74)

Similarly, Leong, Carter, and Stephenson (2013) surveyed early intervention providers in Malaysia and Singapore and found that even though half of the participants reported that research evidence on the efficacy for sensory integration was the reason that they employed this intervention, few reported using academic journals as sources of information about sensory integration. In contrast, 74.2% of the Australian early intervention



professionals surveyed by Paynter et al. (2017) reported that they used research literature (e.g., academic books and academic journals) as sources of information about intervention practices for ASD, and 60.6% used treatment reviews (e.g., “good practice guidelines”). These participants rated both research literature and treatment reviews as trustworthy sources. However, more commonly used sources of information included internal professional development (100% of participants), therapists (e.g., speech therapists; 97%), workshops or other external professional development (89.4%), teachers (81.8%), general web searches (e.g., google; 78.8%), and parents of children with ASD (77.3%). The source of information most commonly used by the sample of allied health professionals working with individuals with ASD but not limited to the early intervention years was workshops or external professional development (100%; Paynter et al., 2018). Ninety-nine percent of participants in Paynter et al. (2018) reported receiving information from research literature, 77.8% from research and professional websites, and 72.7% from treatment reviews. Other frequently used sources included other therapists (99%), internal professional development or training (95.9%), autism associations or organizations and information from general web searches (both 89.9%), teachers and parents of children with ASD (both 89.8%), and professional associations (87.9%).

The allied health professionals surveyed by Paynter et al. (2018) rated research literature as the most trustworthy source of information, followed closely by workshops or other professional development, research and professional websites, treatment reviews, and internal professional development or training which also received a high mean rating of trustworthiness. The source of information with the highest mean trust rating received from early intervention professionals in the Paynter et al. (2017) study was internal professional development. Workshops or other professional development were also considered to be trustworthy, along with a range of other sources including therapists, research literature, and websites (Paynter et al., 2017). This indicates that early intervention and allied health professionals

may attribute a similar weight of importance to information received from sources of research evidence to that received from other sources such as other professionals and professional development. Stahmer et al. (2005) also observed that the participants in their US sample tended to rate interventions as evidence-based if they had attended professional development workshops related to the intervention. In addition, 76.2% of the Malaysian early intervention providers surveyed by Leong et al. (2013) stated that they used sensory integration due to benefits described at a conference. Further, occupational therapists were reported to be the most common sources of both information and training regarding sensory integration in Malaysia and Singapore, and over 80% of the participants in the Leong et al. (2013) study reported that advice from occupational therapists was the reason that they used sensory integration. Findings from these studies in the US, Australia, and Asia suggest that workshops, professional development, and advice from other allied health professionals (such as speech therapists and occupational therapists) may have significant influence on early intervention and allied health professional’s decision-making.

However, similar to parent decision-making, there are very limited data related to the relative importance placed by early intervention professionals on different factors in decision-making. Paynter et al. (2017) asked the intervention providers to rate the level of importance of 15 possible factors in their decisions to use intervention practices. The child’s strengths and needs had the highest mean importance ratings, followed by the family’s values, professional judgment, resources available to implement the intervention at their organization, and research evidence. The factors with the lowest mean importance rating were the interventionist’s university or other post-school training, their own intuition or “gut feelings,” whether they thought the child would enjoy it, and their hope that the intervention would work for the specific child (Paynter et al., 2017). Although 62.1% of participants indicated that research evidence was very important in their decision-making and a further 30.3% considered it somewhat important, there were 8.5% of early

intervention providers in this study who considered research evidence to be unimportant in their decision-making (Paynter et al., 2017). Clearly, for at least some professionals, factors other than research evidence influence intervention decisions.

Goldbart, Chadwick, and Buell (2014) considered the rationales provided by speech therapists in the UK for the intervention approaches that they employed with children and adults with profound and multiple disabilities. Although this study cannot provide insight into the weight of importance placed by these professionals on each of the factors in decision-making, it does provide further insight into the range of factors that influence decision-making. The most frequently stated rationales for the use of intervention approaches were the empowerment, development, and behavioral needs of the individual, followed by the opportunity to develop the communication environment and family and carer skills. Unlike the Paynter et al. (2017) sample, these professionals did not frequently consider the views and wishes of the family/carers as a rationale for using any of the specific approaches and also rarely stated that they considered the views of other professionals (Goldbart et al., 2014). Published research evidence was only sometimes provided as a rationale for the use of the intervention approaches examined. The importance of clinical expertise and theories was also mentioned occasionally across the intervention approaches. Some rationales are provided by the participants that were not anticipated by Goldbart et al. (2014) related to practical and organizational issues, such as availability of resources and service structures.

Related to practical and organizational factors that have been considered in the decision-making of professionals, Cheung, Trembath, Arciuli, and Togher (2013) surveyed Australian speech therapists working with individuals with ASD about specific workplace factors that may act as either barriers or enablers to implementing evidence-based practice. The vast majority of participants (97%) indicated that they considered the application of evidence-based practice (EBP) as necessary in the practice of speech-

language pathology, and 76% indicated that they had searched for research evidence on a regular basis. Interestingly, these participants viewed themselves in the minority in terms of regular practice for speech therapists, with only 23% agreeing with the statement that “Most speech-language pathologists work according to the principles of EBP when providing services to children with ASD” (Cheung et al., 2013, p. 399), and 41% agreed that there was a divide between research and practice. This is unsurprising considering the evidence that there are some early intervention and allied health professionals who report using interventions that are not evidence-based and that research evidence is not always reported to be an important consideration in professional decision-making (Goldbart et al., 2014; Leong et al., 2013; Paynter et al., 2017, 2018; Stahmer et al. 2005). Workplace culture and support were identified by Cheung et al. (2013) as important features that may either enable or act as barriers to the implementation of evidence-based practice. One participant commented

“Management staff of my organization are not clinicians and therefore have limited understanding of the need to use EBP. Resources for accessing research are therefore not deemed to be a priority and service delivery decisions are made from an administrative point of view, rather than being evidence-based.” (Cheung et al., 2013, p. 400)

Time constraints within the workplace and the cost of resources such as subscriptions to journals and professional development courses were identified as further barriers to completing professional reading and other professional development that participants believed were necessary for the implementation of evidence-based practice. Finally, less than half of the participants believed that they had an adequate understanding of the process of evidence-based practice involving “(a) defining questions, (b) identifying sources for clinical evidence, (c) finding research evidence, (d) appraising the literature, (e) applying findings to relevant clinical questions for a specific client’s needs, and, finally, (f) evaluating the effectiveness of this process” (Cheung et al., 2013, p. 401). This indicates that even in a sam-

ple of professionals who appear motivated to employ evidence-based interventions, there may be several barriers to the implementation of these interventions in practice.

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## Recommendations

### Recommendations for Parents

Evidence reviewed in this chapter suggests that parents tend to consider, or are influenced by, a complex range of factors in decision-making. Consideration of research evidence, however, does not typically feature prominently in decision-making. In addition, providing guidance in interpreting research evidence may not necessarily influence parents once decisions have been made (Carlson et al., 2017). This is hardly surprising given the extensive research on human cognitive biases and the well-documented tendency to accept information that is consistent with an established or initial viewpoint and dismiss disconfirming evidence (e.g., Edwards & Smith, 1996; Taber & Lodge, 2006). This has a number of potential implications for interactions with parents.

It is likely to be of importance that parents are provided with clear quality information *before* they have committed to decisions regarding intervention. This should include “red flags” that are often associated with unproven and/or pseudoscientific interventions such as claims of a cure, interventions that address a wide range of different problems, or diagnoses and exclusive reliance on testimonials (see Stephenson, 2004; Travers, 2016). Such material should also include reliable information on the current evidence base for interventions. Unfortunately, while a number of such sites exist for families of children with ASD, such as the Raising Children Network (Raising Children Network, 2006-2018) and Research Autism (The National Autistic Society, 2018) websites, there do not appear to be equivalent sites specifically for families of children with intellectual disabilities. There is also a need for professionals who provide first line of contact to be in a position to offer evidence-based recom-

mendations. This means that such professionals must have an up-to-date knowledge of the evidence base for interventions as well as the skill to work with families to match and tailor interventions to their specific needs. On the flip side, parents should not be reserved in asking professionals to explain the basis for an intervention recommendation. In fact, as suggested previously, such information should be an integral part of the guidance offered by professionals.

Where parents do decide to invest resources into an intervention, particularly an unproven intervention, it is important to have a strategy to assist in evaluating effectiveness. Kay and Vyse (2005) offer some useful suggestions in this regard. They suggest that parents first identify the changes they expect from the selected intervention and attempt to operationally define the relevant behaviors. For example, parents might be anticipating new words to be spoken by their child or a decrease in self-injurious behavior. This approach reduces the risk that any unrelated maturation or development that is observed in the child will be incorrectly attributed to the intervention. Second, some decision rules can be developed with parents to decide when to continue or discontinue the intervention. A test can then be developed to evaluate the intervention. Simple single-case research designs can be adapted to the purpose with the most basic of these designs involving collection of data on the targeted behaviors before and during intervention. While attempting to rationalize a prior decision represents typical human behavior, particularly when individuals are invested in the decision (Kunda, 1990), the general approach suggested by Kay and Vyse (2005) provides parents with an objective approach for evaluating their decisions as well as offering a possible exit strategy.

### Recommendations for Professionals

There is a clear evidence that educational professionals working with individuals with disabilities do not necessarily have an accurate perception of the research base supporting interventions (e.g., Burns & Ysseldyke, 2009; Carter et al., 2011,

2012) and that factors other than the strength of research evidence may weigh strongly on decision-making (Boardman et al., 2005; Carter, Stephenson, & Hopper, 2015). While a variety of contextual factors (e.g., resources, policies, time, student characteristics) should assist in shaping decisions, the degree of research support should undoubtedly be a key consideration. Thus, there is a strong case for improving understanding of the research base for commonly employed interventions among professionals including teachers and early interventionists. This needs to be addressed at the preservice level and updated with in-service training. Caution should be exercised, however, when accessing online sources to identify evidence-based practice. For example, Test, Kemp-Inman, Diegelmann, Hitt, and Bethune (2015) found 43% of websites identified as providing information to teachers about evidence-based practice in special education were not trustworthy.

There are implications for teacher educators as well. It is clear that teacher education programs and in-service professional learning are needed to build an understanding of research, evidence-based practices, and their applications to particular settings (Boardman et al., 2005; Chorzempa, Smith, & Sielo, 2018). Teachers need to look for training in particular evidence-based strategies, but those providing training need to be clear about the impacts on student outcomes and consider the features of interventions that make them acceptable to teachers. The work of Ruppap and colleagues (Ruppap et al., 2018) also demonstrates the need for teachers to carefully consider their attitudes to students with severe disabilities and adopt a position that recognizes the importance of education rather than care.

In addition to making decisions regarding their own practice, some professionals, particularly those in the area of early intervention, may be asked to provide advice to parents, caregivers or other professionals. For example, Leong and colleagues (Leong et al., 2013; Leong, Stephenson, & Carter, 2011) found that advice from occupational therapists was a major factor in the adoption of sensory integration therapy in early intervention centers in Malaysia and

Singapore. In addition, there is evidence that parents both value (Carlon, Carter, & Stephenson, 2015; Dinora & Bogenschutz, 2018; Grant et al., 2016) and may desire more guidance from professionals (Carlon, Stephenson, & Carter, 2015; Grant et al., 2016; Levy et al., 2016). Consequently, a strong argument can be forwarded that it is critical that professionals are up to date with regard to the evidence base for interventions (Carlon, Carter, & Stephenson, 2015; Sansosti et al., 2012; Trembath, Hawtree, Arciuli, & Caithness, 2016). In addition, clearly communicating the research base for interventions to parents can be considered an important component of professional practice (Trembath et al., 2016), and this argument logically can be extended to communication with other professionals. Further, Leong et al. (2013) have argued that organized efforts to establish professional relationships between academics and service providers may assist in the dissemination of accurate information to professionals.

## Recommendations for Future Research

A number of recommendations for future research arise from this chapter. We currently have substantial research on decision-making of parents of children with ASD but very limited research on other diagnostic groups. Given the distinctiveness of ASD, it is not reasonable to assume that the results of research with this diagnostic category are automatically generalizable to other groups. There is a clear need for further research on other populations. Similarly, the vast majority of the existing research relates to children who are of preschool and school age. Consequently, there is a prescient need for research with regard to decision-making processes with regard to adults who may be accessing vocational services or living in supported residential settings. In particular, there is very limited intervention research with regard to supporting parents and teachers and individuals with intellectual disabilities in more effective decision-making.

Research on teacher decision-making for students with intellectual disabilities is also limited. There has been recent interest in the decision-making of teachers of students with severe disabilities, including severe intellectual disabilities but mostly relating to teachers of segregated classes. There is much less research on teachers of students with mild intellectual disabilities, in both inclusive and segregated settings. Although there has been a lot of interest in promoting the use of evidence-based practices by teachers, there is little work that explores the reasons why teachers decide to use or not use evidence-based practices. Future directions for research would include more work on teacher decision-making, especially for students with less severe intellectual disabilities, and more work on teacher perspectives on the use of evidence-based practices.

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