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Ethical Issues in Assessments with Infants and Children

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When conducting assessments with infants and children it important for psychologists to be mindful of the ethical issues that may arise. Ethical issues may arise when proper procedures for performing assessments are not carried out. The present review will focus on the following ethical issues as they pertain to assessments with infants and children: obtaining parental consent, respecting children's autonomy, maintaining confidentiality, separating children and parents during assessments, and using multiple sources of information and appropriate measures. Guidelines for ensuring the competent evaluation of children are then offered, with attention to the dynamic nature of the assessment process and the critical role of parents.

A number of ethical issues may arise when psychologists provide assessments to infants and young children. These issues can occur due to the differing needs of children, their parents, and professionals. The present review will examine some of these issues with regard to parental consent, children's rights, confidentiality, separation of parent and child during assessment, and the use of multiple sources of information and appropriate measures. First, a brief discussion of the assessment process will be presented as a framework for conceptualizing these issues.

The Assessment Process

An assessment is an "ongoing process by which qualified professionals, together with families, through standardized tests and observation, look at all areas of a child's development: motor, language, intellectual, social/emotional and self-help skills" (ZERO TO THREE: New Visions for Parents, 1997). An assessment may be performed to determine if infants and children are meeting developmental norms, to identify children with disabilities and those who may be at risk, to diagnose or confirm the presence and extent of a disability, to plan a program or appropriate intervention, or to demonstrate a child's knowledge of certain skills and accomplishments (Meisels & Fenichel, 1996).

Most often the assessment process is initiated by either a parent or a professional. It is quite common for a child's teacher or physician to notice a child behaving or developing out of the ordinary and to then consult with the child's parents about performing an assessment to learn more about the problem area. Likewise, parents often contact teachers, physicians, or other professionals out of concern for their child's development or atypical behaviors observed in the home. Once an assessment is deemed necessary, the process begins with the parents' consultation with the assessment professional. The child's strengths and challenges, as well as the concerns and questions of the parents, are discussed. It is then decided which type of assessment (developmental, family, multidisciplinary, or play-based) is most appropriate for the child. Depending on the type of assessment implemented, the child's parents, physician, schoolteacher, or counselor may assist in the process either directly or indirectly (The ZERO TO THREE: New Visions for Parents, 1997).

Assessing a child's functioning during the first three years of life is especially important, since it is a period of constant growth and development (Meisels & Fenichel, 1996). The ZERO TO THREE: National Center for Infants, Toddlers, and Families (1996) focuses on providing support, education, training, and policies for parents, caregivers, and professionals to help advance the healthy development of infants and young children. In 1996, ZERO TO THREE assembled a multidisciplinary Work Group on Developmental Assessment to "identify both problems and approaches in current assessment paradigms, policies, and practices" (Meisels & Fenichel, 1996, p. 5). This group also formulated a list of appropriate principles pertaining to assessments as well as practices to avoid in assessments; these will be utilized as a general framework for the present review.

Obtaining Parental Consent

The American Psychological Association (2002) defines informed consent as a decision made by an individual that is informed, voluntary, and rational. In the case of parents providing consent for their child to be assessed, they are considered "informed" when they have been given substantial information about the assessment and its procedures, including the potential consequences, risks, and benefits. Parents should be provided with information concerning their child's assessment in a language that is understandable

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to them, and their decision must be voluntary and free from coercion from professionals or family members. Finally, parents must have the ability to make a rational decision concerning their child's participation in the assessment procedure, which means they must be able to weigh the possible risks and benefits and to make an informed decision whether to allow their child to be assessed (Ambuel & Rappaport, 1992; Kaser-Boyd, Adelman, & Taylor, 1985).

Parents serve as the decision-making guides for children who have not yet reached the age of majority, which is 18 years (Department of Health and Human Services, 1991). Parents or guardians are entitled to provide permission because they have legal responsibility and, in the absence of abuse or neglect, are assumed to act in the best interests of the child (Krener & Mancina, 1994). It is important that parents provide their child with the best possible care while ensuring that they are learning and developing appropriately, and as such it is often necessary for them to have their child evaluated in different domains so that they can learn more about their performance and developmental progress. Various states and child centers recommend that children of certain ages be assessed as an effort to ensure that the child's development is being nurtured to the fullest extent possible (Meisels & Fenichel, 1996).

Obtaining parental consent is one of the most frequent challenges faced by psychologists and other professionals in the school system. Ethical issues can arise when proper procedures for performing the assessment are not carried out, when parents do not agree with the requirement for assessments, or when parental priorities are ignored or underestimated by professionals (Greenspan & Meisels, 1996). The following case example provided by Knauss (2001) illustrates how easily problems in this area can arise:

> Shortly after being hired by a school district, a new school psychologist was given a long list of children who needed psychological testing. The new psychologist's supervisor explained the purpose of the testing, which was to obtain needed services for the children. She then mentioned that she had already scheduled the children for testing. The supervisor then implied that since the testing was part of their educational program, parental consent was not necessary. (p.2).

In thinking about this example, was the newly hired psychologist's supervisor correct in not obtaining parental consent? If professionals from the school say it is appropriate to proceed without parental consent, should these guidelines be followed? Finally, what ethical principle was violated or ignored?

Ethical codes require that informed consent be obtained from the appropriate individual before services are provided. Since infants and young children do not yet have the ability to make their own decisions, parents are required to provide informed consent as the first step in beginning the assessment process. Therefore, it is incorrect to assume that school professionals can substitute the decisions of the children's parents. However, an exception to this case would be if the parents voluntarily agreed to allow routine assessments for their child at the time of enrollment in the school (APA, 2002). The APA (2002) does not require psychologists to obtain informed consent when "informed consent is implied because testing is conducted as a routine educational, institutional, or organizational activity" (p.13). Nevertheless, communicating with parents is often essential in establishing a basis for an effective home-school relationship (Knauss, 2001).

Respect for Children's Rights

Although infants and young children do not yet have the decision-making abilities to provide informed consent, they do have several rights. By the ethical principles of autonomy, beneficence, and justice, children have the right to be treated with respect and be given proper care (Knauss, 2001). The principle of autonomy refers to the duty of professionals to protect and encourage an individual's choices. Studies have found that parental support of autonomy leads to positive outcomes for children across different developmental periods (Allen et al., 1994; Mattanah, 2001) and that by actively encouraging children to make independent decisions and to express themselves, parents can begin to foster a sense of autonomy (Shaffer, 2002). But regardless of whether autonomy has been optimally fostered by parents, professionals should be mindful of the child's needs as well as those expressed by the parents. Beneficence refers to the responsibility to respect and make choices that are in the best interest of the individual. The well being of the child takes precedence over any needs of society to conduct the assessment (e.g., providing public statistics or conforming to state requirements). In the case of assessments, professionals should protect the health and safety of children by choosing assessments that are deemed necessary and sensitive to their specific needs. Finally, the principle of justice expects that those working with others behave in ways that are fair and honest (Blustein, Dubler, & Levine, 1999; Fisher et al., 1996), and that any applicable benefits are distributed equally among individuals (National Commission, 1979). When conducting assessments, examiners must be mindful of treating children as equals. For example, if assessment results indicate that a child might benefit from a special education program, the decision of whether to place him or her in such a program should be based on need, regardless of background or other criteria (National Commission, 1979). Overall, these ethical principles serve to remind professionals of the appropriate ways in which individuals, including children, should be treated.

The most common of these issues to arise in the assessment of infants and young children is neglect of autonomy. Because young children are not developmentally capable of voicing their own opinions and desires, their capacities can often be overlooked. This is especially relevant when a child has a developmental delay or other issue that has led to difficulty interacting socially and communicating needs. Some assessment procedures may not adequately break

through these developmental barriers to uncover the child's specific strengths and weaknesses (Greenspan & Meisels, 1996). For this reason it is important that professionals engage in discussions with the child's parents about the child's developmental history and capacities in order to gain a better understanding of the child's behavior.

Children's Right to Confidentiality

At present, clear guidelines do not exist as to when children of certain developmental capacities have the right to confidentiality. In most areas, the law does not provide children with this right (Mitchell, Disque, & Robertson, 2002). This position stems mainly from the notion that parents serve as the custodians and decision-making voices for children. Since minors cannot legally provide informed consent, researchers are encouraged to respect their preferences by seeking their assent to participate in the assessment process when developmentally appropriate (American Psychological Association, 2002; DHHS, 1991). Assent is the means of involving minors, typically seven years of age or older, in decisions affecting them, "an interactive process between a minor and researcher that involves developmentally appropriate disclosure about the procedures, and solicitation of the minor's willingness and preferences regarding participation" (Committee on Bioethics, 1995, p. 316).

It is important to obtain assent from children when it is developmentally- and age-appropriate because it includes children in the decision-making process. For this reason, assent is viewed as a benefit to the child. Parents should nurture the moral growth and developing autonomy of their child by giving them the opportunity to provide assent. Assent sets a lower standard of competence than informed consent in that it does not require the depth of understanding or reasoning ability required for the latter (Weithorn, 1983). However, giving children the opportunity to provide assent, to the extent that they are able, allows them the chance to choose whether or not to participate in the assessment process.

The Separation of Children and Parents during Assessments

The ZERO TO THREE: National Center for Infants, Toddlers, and Families (1996) has outlined several practices that should be avoided in the assessment procedure. One of these is "Young children should never be challenged during assessment by separation from their parents or familiar caregivers" (p. 23). In other words, children should not be separated from their parents when the separation might pose a problem in conducting the assessment or affect the reliability of the evaluation. When professionals evaluate children without respect for this principle, conclusions may be unduly biased. For example, if a child has difficulty interacting with others and is separated from his or her parents for an assessment, he or she may be difficult to engage or may behave in a detached and unpredictable manner. Clearly, such testing conditions are not optimal.

The potential difficulties of separating a child from his or her parents are further illustrated by the following example, derived from a case offered by Greenspan and Meisels (1996):

> When a 3-year-old named Sarah needed an assessment to evaluate her level of receptive and expressive language, the examiner requested that her mother wait outside the testing room. The mother explained that her daughter would be more cooperative if she were allowed to remain in the room. The examiner repeated the policy about having only the patient in the examination room. Sarah's mother made it clear that she was hoping to test her daughter's language ability, not her readiness to leave her mother. The examiner told Sarah's mother, with a patronizing show of patience, that the results of the test might not be the same if she were to stay in the room. She agreed with the examiner, but also wondered how the doctor expected to get any test results at all from a child who was nervous and withdrawn as a result of being separated from her mother. After completing the test, the examiner observed that Sarah was not very cooperative for a 3-year-old child.

The professional conducting this assessment may conclude that the child is uncooperative and has attachment issues. This may not have been the conclusion if the parent had been allowed to be present for the assessment (Greenspan & Meisels, 1996). If professionals acknowledge that children behave differently depending on whether their parents are present, they may choose to allow the parent to be present during the assessment until the child becomes comfortable enough to work with the examiner alone (Morse, 2001).

Need for Multiple Sources of Information During Assessments

Another guideline for assessments provided by The ZERO TO THREE: National Center for Infants, Toddlers, and Families (1996) is "Assessment should involve multiple sources of information and multiple components" (p. 17). "Multiple sources" can include direct observations of the child, interactions between the child and a caregiver, and the family system. In addition, it is important to obtain background information on the child's capacities in different areas of development, as well as assessments of specific areas of the child's functioning (Greenspan & Meisels, 1996). By using various types of information, psychologists can obtain a more complete picture and reach more comprehensive conclusions about the child's development (Greenspan & Meisels, 1996; National Association of School Psychologists, 2000).

Use of Appropriate Measures During Assessments

The National Association of School Psychologists (2000) mandates that "school psychologists be knowledgeable about the validity and reliability of their instruments and techniques, choosing those that have up-to-date standardization data and are applicable and appropriate for the benefit of the child" (p. 27). Unfortunately, it is often the case that infants and young children are assessed using instruments and procedures developed for older children (Greenspan & Meisels, 1996). There exist very few assessment instruments that measure the specific developmental challenges and characteristics faced by young children and their families (DeMers, Fiorello, & Langer, 1992). This lack of appropriate measures for infants and young children can pose problems for professionals who are administering the assessments. Although professionals may be aware of the limitations of the existing approaches for assessing young children, they may still often use procedures that are designed for school-aged children. Not only is it unethical to use inappropriately normed and validated procedure, it is also unwise to draw conclusions from the obtained results, which may be misleading to parents (Greenspan & Meisels, 1996). Professionals should make every effort possible to ensure that tests and procedures are used in ways that protect the rights and promote the well being of the children being assessed.

The issue of using appropriate measures applies perhaps especially to professionals who assess children with significant disabilities. When choosing an assessment for a child with significant motor, sensory, or cognitive impairments, examiners should be mindful of the kinds of tests they use and the conclusions they draw from the results. Examiners should ask themselves the following questions: Can this test answer specific questions about the child's development? How do other children with this type of disability perform on the test? (Miller & Robinson, 1996). Most tests that are norm-referenced assume that the child being assessed is similar to those included in the original sample. Examiners who are testing children with motor and sensory impairments need to be aware of the fact that children these impairments are often excluded or not eligible to be included in the standardization of developmental instruments (Miller & Robinson, 1996). As noted by the National Fair Access Coalition on Testing (2002), “In choosing a particular test, the assessment professional…is responsible for reviewing test manuals or materials to ascertain the test’s applicability in measuring a certain trait or construct.” If examiners do not take these facts into account when assessing children with disabilities, they run the risk of violating one of the basic guidelines of administering assessments: that the examiner has knowledge of the validity, reliability, and standardization procedures of the test (National Association of School Psychologists, 2000). Not only is violating this guideline unethical, but a child who is assessed using an inappropriate measure may be judged to lack certain abilities (Miller & Robinson, 1996).

Some of the assessments that have been widely tested and proven to be valid and reliable measures of infants’ and young children's abilities include the Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al., 1992), the Neonatal Behavioral Assessment Scale (Brazelton, 1973), and the Bayley Scales of Infant Development II (Bayley, 1993). The PEDI, designed for use with children from the ages of six months to seven years, examines a child's ability to function independently while also observing what the child can do with assistance. Since this measure has been developed with standardized scores that can be used to evaluate child's growth over time or a child's anticipated development, it is appropriate to use with children who have impairments (Miller & Robinson, 1996). The Neonatal Behavioral Assessment Scale is widely used by professionals who work with infants and families in hospitals, clinics, and educational settings and is designed to examine newborns and infants up to two months of age (Brazelton, 1981). It provides the examiner with a behavioral description of the infant, which includes the infant's strengths, adaptive responses and possible vulnerabilities; this description is shared with parents by the examiner to develop appropriate care giving strategies aimed at enhancing the earliest relationship between infants and parents (Brazelton, 1981). The Bayley Scales of Infant Development, Second Edition (BSID-II) is an individually administered test that assesses the cognitive and motor development of infants and children from the ages of one month to 42 months. The main purpose of the test is to diagnose developmental delay and plan intervention strategies (Bayley, 1993). Using these and other age-appropriate assessments can help professionals design useful interventions and find appropriate special education placement and services when necessary.

Guidelines and Recommendations for Assessment Procedures

When conducting assessments, psychologists and other professionals should be aware of the issues raised in this review to ensure that they are evaluating infants and children with competence and care. By being responsive to the differing needs of children, their parents, and other professionals, examiners can ensure that proper procedures are being followed, that parents are being adequately informed about the procedures and results, and that parents’ concerns are being addressed and respected (Greenspan & Meisels, 1996).

In order to ensure that the assessment process is being carried out appropriately, there are certain guidelines that can be followed and applied to the ethical issues discussed. The examiner should keep in mind the following questions highlighted by Barrera (1996): "Am I communicating with the child and family in a way that will elicit desired responses?" "Do the child's and family's responses indicate their true abilities and potentials?" "Is the child exhibiting age-expected behaviors and skills for his or her community and peer group?" "Is the assessment doing an adequate job

of highlighting the child's strengths and weaknesses?" (p. 79). By viewing the assessment procedure as an active process and keeping in mind these questions, examiners can ensure that they are evaluating the child and his or her family with competence and care.

Since parents serve as the voice and decision-making authority for their children in the assessment process, psychologists should work to prepare parents for their roles as participants in the assessment of their infant or young child (Popper, 1996). Examiners need to be aware that whether parents are having their child assessed for the first or second time, they will usually be protective yet cooperative with the examiner. Professionals should be aware of parent's feelings and share information with them concerning the assessment (Popper, 1996).

Psychologists and other examiners should remind parents of the fundamental goals in the evaluation process. Parents are there to "be the parent." (Popper, 1996). Their knowledge about their child makes them the expert; therefore, their input is important and should be acknowledged. In addition, parents should be reminded that they do not have to agree with all the information that results from the assessment. If parents feel that their child is being described in a manner that they do not agree with, they should be made to feel that they can voice their disagreement (Popper, 1996). Treating parents as active participants in the child assessment process can lead to more beneficial outcomes for the child, the parents, and the assessment professional.

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