

# THE IHS PRIMARY CARE PROVIDER

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## The Bayley Scales of Infant Development - Second Edition and Its Use with Navajo Children: Implications and Suggestions

*Mary McLellan, PhD, Associate Professor, and Coordinator, School Psychology Program; Marlene Hartmann, MS, Student; and Karen Applequist, PhD, Assistant Professor, all from Northern Arizona University, Flagstaff, Arizona*

### Introduction

Researchers studying neurological processes are now suggesting that the first years of life provide the best “window of opportunity” for children to develop and learn.<sup>1</sup> Understanding normal developmental patterns becomes critical when making informed decisions regarding the identification of children whose development may be compromised. This paper will present research regarding the performance of young Navajo children on a standardized developmental measure and will discuss the implications for health care providers involved in the identification, referral, and care of very young Navajo children whose developmental progress may be in question.

Recognizing that some children need help in the developmental process, Public Law 99-457 was enacted in 1986. Parts B and C of this law are important to infants, toddlers, and young children with developmental delays or who are developmentally at risk. Part B extends educational services previously mandated under the Individuals with Disabilities Education Act (IDEA) to preschool children. In practice this means that children age 3 to 5 with developmental delays can receive special education services and be financially supported in Head Start programs and public preschool programs.

Part C of IDEA establishes the framework for states to provide early intervention services to infants and toddlers with developmental delays and to their families. Early intervention includes a broad array of health, therapeutic, and educational services considered beneficial to children who are developmentally delayed or who are at risk for developmental concerns.

An Individualized Family Service Plan (IFSP) is created for each child and family participating in early intervention services under Part C. The IFSP is based on the family’s resources, concerns, and priorities, and outlines the desired outcomes for the child and the types of services needed. The three states that include Navajo reservation lands have state plans for providing services under Part C. The Growing in Beauty program administers and coordinates the Part C services for the Navajo Nation.

Guidelines for identifying children for Part C services were established in the Federal legislation. This law requires states to serve infants and toddlers who are “experiencing developmental delays or have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay” [Education of the Handicapped Act Amendments of 1986,

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Section 672(1)]. Some variation in qualifying criteria will occur from state to state.

Historically, physicians have initiated referrals for developmental evaluations and early intervention services earlier and more frequently for those children having physical or mental conditions generally associated with developmental lags, such as cerebral palsy or Down Syndrome.<sup>2</sup> However, physicians are more apt to take a “wait and see” approach with children who may be demonstrating delays in their development, but who have an otherwise unremarkable medical history.<sup>3</sup> While this approach may not be inappropriate for some children, it remains within the purview of clinical judgement. The authors contend there are some factors the physician should consider when this occurs.

The American Academy of Pediatrics and Federal legislation recommends developmental screenings.<sup>4</sup> Although there is no standard protocol, developmental screening may involve standardized screening measures such as the Denver II<sup>5</sup> or other developmental checklists, clinical observations, consideration of family history, and level of parental concerns. A screening that identifies concerns would merit a referral for a developmental evaluation, which would involve more extensive, in depth assessment of a child’s developmental functioning. Health care providers are often placed in a position of making the decision to refer a child for a developmental evaluation.

Health care providers working within IHS must frequently rely on clinical judgement when determining the developmental status of young children. There have been no reported studies that specifically address how Navajo children perform on standardized developmental measures. The research portion of this study undertook the task of obtaining standardization data on Navajo children using a standardized measure of development, The Bayley Scales of Infant Development - Second Edition. This article presents the research findings and addresses potential application of the findings.

### Research Methodology

Two of the authors (MM and MH) undertook a study of how Navajo children perform on the Bayley Scales of Infant Development - Second Edition (BSID-II). The BSID-II is a standardized measure of development that assesses both cognitive and motor development for children from birth to age 30 months. The scores obtained from the BSID-II are standard scores with a mean of 100 and a standard deviation of 15. The BSID-II has two scales, the Mental Scale that yields a Mental Developmental Index (MDI) score and the Motor Scale that yields a Psychomotor Developmental Index (PDI) score. The test is administered in a play-like format with the child completing various tasks that are presented. As the chronological age of the child increases, so do the complexity of the tasks and the developmental expectations.

The Psychological Corporation revised the BSID-II in 1993, and the impact of the revisions has not been fully researched. In particular, how Navajo children perform on the BSID-II has not been investigated prior to this study. Ninety-three Navajo

children, between the ages of 3 and 26 months, were administered the standard version of the Mental and Motor Scales of the BSID-II. This sample of convenience was obtained through recruitment of children from the Kayenta and Tuba City IHS health clinics. Children within the age ranges of 3 to 24 months were identified based on registration information, and parents were approached to determine if they would be willing to participate with their children. An equal representation of children across the age ranges was recruited. Children were typically visiting the clinic for well-child checks or with siblings who had a clinic appointment. The parents of the children were interviewed and each child included in the sample had an unremarkable health or developmental history. The children who were included in the study were not suspected of having developmental delays based on medical and parent report.

### Results

The BSID-II was administered and scored according to standard procedures. The Mental Developmental Index and the Psychomotor Developmental Index scores were calculated for each child. Means and standard deviations of the index scores for the entire sample were calculated and plotted to understand the distribution of scores. After reviewing the scatter plots for both indexes, it became clear that the children’s performance on the motor scale was essentially identical to the normative sample across the age range of the sample. The results from the Mental scale suggested children up to 15 months of age performed in a manner consistent with the standardization sample. The mean MDI score for children above 15 months was approximately one standard deviation below the mean of the standardization sample. The scores dropped to the point that a disproportionate number of children would be considered eligible for services under Part C if the developmental pattern unique to Navajo children were not taken into account. Since the children performed at approximately one standard deviation below the mean, and determination of eligibility for services is based partly on test scores, more Navajo children could be identified for services than would be expected in the general population.

The results are presented in Table 1 as means and standard deviations for three age groups. The decline in the Mental Developmental Index scores (MDI), noted above, is clearly demonstrated in the table. The mean PDI scores are not shown because they were all within 5 points of the normative mean.

**Table 1. Mean MDI scores for three age groups**

Age in Months (N)	Mean MDI Score	MDI Standard Deviation
< 9 mo (32)	100.38	9.19
9-15 mo (31)	102.61	9.74
≥16 mo (30)	82.67	12.17

To provide insight into the decline in scores illustrated in Table 1, an item analysis was completed. A discussion of the administration procedures and examples of items of concern fol-

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lows. The BSID-II is administered as sets of items, with a child's chronological age providing a point to start the test administration. Item sets are constructed to minimize administration time and maximize the chances that the child will succeed on items administered early in the test session as well as be challenged as the session progresses. The individual items from item sets above 14 months were identified as being particularly challenging for the children participating in this study. One example of this was their performance on form board puzzles contained in the 14-16 month item set. Two form boards are introduced at this age group, but the criteria for success changes with the child's age. For example, at 14-16 months the child is expected to correctly place only 1 piece of a 9-piece form board, and identify a circle from three shapes on another board. Children who are older would be expected to complete the form board within a specific period of time. The majority of the children in our sample had difficulty completing this task in an age-appropriate manner.

A majority of children ages 14-16 months could not name body parts or show their shirt or shoes upon request. In general, items that required verbal responses were difficult. Parents were always present during the evaluation and they were instructed to translate any questions or directions they felt would assist their child. If children responded in Navajo, their responses were considered correct. Therefore, the dominant language of the child was taken into consideration.

It should be noted that the challenges and successes noted above were based on 29 children out of the population of 93, so the sample size was small. The 64 children not discussed in this section were below 15 months of age, and their performance was similar to children in the normative group. The children being discussed were in the 15-24 month age range. Also, since the items are developmentally based, older children may have been able to accomplish the tasks, but not at the expected age. The results do not suggest that Navajo children are unable to do particular tasks, only that the skills may emerge later than the normative sample of children. The normative sample contained minimal representation of Native American children. Although the sample size is small, these findings may be instructive as they relate to our screening and referral practices.

## Discussion

Unless a child has a condition generally associated with developmental delays, the decision to refer a child for a more in-depth developmental evaluation can be a difficult one to make. Health care providers who see children routinely and conduct periodic screenings of their development often make this decision. It is important for individuals who are in this position to understand how children of Navajo descent perform on standardized measures and why a more intensive evaluation of the child may be desirable.

The primary reason for referring a child for a more extensive developmental evaluation is to obtain more in-depth information about the child than health care professionals generally have the time to gather. This information will be useful in

providing a more complete developmental profile of the child in your care. Second, if the child is demonstrating developmental delays, the evaluator is in a position to provide the family with further information regarding the developmental expectations for their child. The evaluator can also recommend in-home activities that will help the child to develop age-appropriate skills. In some instances evaluations can result in a referral of children for early intervention services so the family can receive ongoing assistance and training in techniques and approaches that will help their child.

The findings reported in this study suggest that Navajo children above the age of 15 months perform at a level divergent from the normative group on the BSID-II. Developmental measures include activities or tasks that children typically experience; hence, the play-like format of the test administration. One possible hypothesis about why there was a difference in performance of the Navajo children could be that their caregivers do not engage in activities considered typical by the test developers. For example, asking children to name or point to body parts was an activity that was not typically completed at the expected level by the children in this sample; this could be indicative of a different style of parenting or emphasis on different types of skill development. The question could be, How important is teaching names of body parts at age 18 months? Does a child knowing them constitute an important developmental milestone? Children on the Navajo reservation are inevitably placed in a preschool with a curriculum designed to prepare children for public school. Therefore, the expectations are placed on success in school. Given these expectations, should children have the opportunity to learn age-appropriate developmental tasks at a young age? This could be accomplished through the introduction of these expectations in an office visit or more extensive follow-up with developmental evaluation specialists.

The results of this research suggest that there may be some differences in the developmental rates of Navajo children compared to other ethnic groups, as measured by one standardized test. One clear conclusion from this research is that children should be introduced to the tasks that will be expected of them in school, to give them a fair chance at success in school. Many children living on the Navajo reservation are eligible to attend Head Start when they turn three years of age. These programs provide the educational basis for young children to develop skills that will prepare them for entering public or BIA schools. The curriculum of Head Start is predicated on developmental expectations for children age three to five years. It may be doing a child a disservice to knowingly prevent them from entering Head Start with skills and abilities similar to other children. In those instances when a child may lack age-appropriate skills, we should provide the child and their parents with the extra help he/she may need to gain those skills. In many cases, this may be as simple a task as providing information to the family about what types of toys to have available for the child.

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Future research should address the extent to which the results found in this study generalize to a larger and more representative sample on Navajo children. In addition, a wider age range would provide some insight into the dynamics of the results from the present study. Longitudinal research could provide insight into the implications of early introduction of the tasks considered typical in the predominantly Anglo sample used to construct the BSID-II.

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# Indian Health Service Clinical Pharmacist Involvement with Nephrology Patients

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*Cynthia P. Smith, RPh, MPH, Pharmacy Department Line Supervisor and Pharmacy Quality Improvement Coordinator, Gallup Indian Medical Center, Gallup, New Mexico*

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Studies have demonstrated the value of having clinically oriented pharmacists in both inpatient and outpatient hemodialysis settings. These studies illustrate that pharmacists can provide a wide variety of pharmacotherapeutic services to acutely ill or ambulatory dialysis patients with a high acceptance rate from medical staff. Additionally, they demonstrate that clinical pharmacists can have a positive impact on patient outcomes in this complex population.<sup>1-4</sup>

By the time a patient with chronic renal failure starts treatment such as hemodialysis, medications are often needed to correct anemia, hypertension, phosphorus levels, and nutritional deficiencies. One study showed that patients with chronic renal failure were on an average of ten prescription medications and two over-the-counter medications.<sup>5</sup> Another study of two dialysis units found that the average number of medications used by each patient, eleven, was slightly higher than the United States Renal Data Systems (USRDS) average, which is nine.<sup>6</sup>

Compliance with this quantity of medications can be a problem. Many dialysis patients are elderly, adding to compliance concerns.<sup>7,8</sup> Interactions between prescribed medications can alter their effectiveness. One common interaction occurs between calcium (prescribed as a phosphate blocker) and iron supplements (prescribed for anemia).<sup>9</sup>

Several studies have documented the effectiveness of patient education on medication compliance. One found that long-term continuous ambulatory peritoneal dialysis (CAPD) or

hemodialysis patients missed more doses of phosphate binders than their antihypertensives and calcitriol, and this correlated with poorer comprehension as to why phosphate binders were prescribed.<sup>10</sup> Another study found that cultural differences in a Native American population led to barriers in compliance. Being on dialysis for more than 18 months, an inability to speak English, being unmarried, having an eighth grade education or less, and not doing one's own shopping or cooking yielded an increased risk of noncompliance.<sup>11</sup> Yet another study showed an association between the occurrence of certain adverse drug outcomes and patients' lack of knowledge about and poor perceptions of drugs.<sup>12</sup>

The pharmacists at Gallup Indian Medical Center (GIMC) appreciated a deficiency in drug understanding among hemodialysis patients at that facility. The pharmacists decided to act on this deficiency, and created a Pharmacy Nephrology Clinic.

## Clinic with Two Sets of Patients

The Pharmacy Nephrology Clinic at GIMC has two separate patient rosters and locations. With one set of patients, the pharmacist works with the nephrologist in the Internal Medicine Clinic at GIMC. The nephrologist sees approximately ten patients each clinic, twice a month. These patients are seen for a variety of reasons, such as follow-up of acute renal failure, post-op renal transplantation, or end-stage renal disease not yet requiring dialysis. The pharmacist interviews the patient for medication history, reviews lab work, and determines if medication orders for refills will be needed that day.

The second set of patients are hemodialysis patients cared for by the Dialysis Unit of Rehoboth McKinley Christian Hospital. This dialysis unit is not part of IHS; the patients are

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seen by physicians who have privileges at both hospitals. The GIMC pharmacist participates in the monthly Patient Care Conference sessions discussing patient drug therapy with the nephrologist, nurse, dietitian, and social worker. Even though all patients are not eligible for care at GIMC, the pharmacist is involved in discussions of all dialysis patients' medication therapy. After Patient Care Conference, a 60-day supply of medications is delivered to all GIMC-eligible patients at the Dialysis Unit.

### **Clinical Pharmacist Involvement**

The author initiated dialogue with James Whitfield, MD in fall 1998 about the possibility of pharmacist involvement with his nephrology patients. Dr. Whitfield is a consultant nephrologist with one morning clinic at GIMC every two weeks for GIMC patients. We began completing patient medication histories as a part of his Nephrology Clinic in Internal Medicine in October 1998. As of the time this paper was written, we have participated in 26 clinics, interviewing a total of 83 different patients (203 total interviews).

The pharmacist assesses patient knowledge of medication and reviews compliance. Information is relayed to the physician prior to his visit with the patient. During the interviews reviewed for this paper, fifty-three patient encounters (26%) identified patients not taking their medications as ordered. At 83 encounters (41%), patients were identified as not needing refills of medication that day because medications had been filled prior to the visit through their regular internist appointment. This information saved the patient time and the institution money since the chart would not need to go to pharmacy to have medications filled. Another advantage of pharmacist involvement in the clinic is that the pharmacist and the patients have an opportunity to establish a relationship before the patients enter hemodialysis.

Dr. Whitfield later spoke with the other two physicians involved with patient care at the RMCH Dialysis Unit, who agreed to allow a pharmacist to participate in the Patient Care Conferences. The GIMC Pharmacy Nephrology Clinic at the dialysis unit started in February 1999. We currently fill medications for 43 of the 105 hemodialysis patients at the Unit. Each month the dialysis secretary sends us a list of patients who will have Patient Care Conferences. She also sends us the report from the last conference, which includes a review of recent hospitalizations, laboratory results, and a list of medications.

Before the Patient Care Conference each month, the pharmacist reviews the charts of the patients who receive their medications at GIMC. Orders in the charts in the dialysis unit are compared with the medications filled in the pharmacy at GIMC. PCC (patient care component) sheets are printed off a database for medication filling. At the Patient Care Conference the patient's medication therapy is discussed. Any information the pharmacist has obtained either through patient interview or chart review is shared. Changes or new medication orders are recorded on the same PCC sheet that was used for the refills. A

60-day supply of medication is filled the day of the Patient Care Conference and is delivered to the patients at the dialysis unit following the conference. The pharmacist counsels the patient on their medications, with emphasis on any new medications or changes in dosing regimens. The pharmacist also ascertains compliance based on patient reports of amounts of medications remaining at home.

Beyond this effort, pharmacists have interviewed 45 dialysis patients on the dialysis unit. Interviews included questions regarding knowledge about medication use, perceptions of importance of medication use, proper dosing regimen (especially important for phosphate binders), compliance with medication regimens, and the importance of obtaining refills. Twenty-five patients (57%) were identified as not taking their medications as prescribed, with 23 patients (51%) admitting to not taking their phosphate binders at every meal. Information obtained from the interviews was relayed to the physician and dietitian orally and through the use of a written progress note.

### **Pharmacy Department Benefits**

Having a pharmacist involved in the nephrology clinic and dialysis center has helped the pharmacy department become proactive, ultimately reducing the internal pharmacy workload. The charts of patients from Nephrology Clinic in Internal Medicine don't come to the pharmacy unless medication refills are actually needed (as determined by the pharmacist in the clinic). Previously, refills would be filled and then later returned to stock when the patient didn't pick them up. The refills for the dialysis patients are filled first thing on the mornings of Patient Care Conference for a 60-day supply of medication (half the patients are reviewed each month) before the Pharmacy gets busy. We modeled this after the success we had had with rescheduled appointments from the Internal Medicine Clinic.<sup>13</sup>

Before pharmacist involvement in the dialysis unit was initiated, usually a proxy would come in after dialysis bringing in empty vials for a 30-day refill. There was no way to verify that these medications were still the ones the physician wanted the patient to be on. Refill requests often came in the afternoon, in the evening, or on weekends when the pharmacy was busy or staffed by only one pharmacist. The pharmacist would have to identify the patient as one living in our service unit, order the medical chart, wait for the chart to be delivered, write up the PCC encounter form, and then fill the order. The result was a long wait for medication and a lot of work for the pharmacist. Before the pharmacist involvement, the attending physician would write new prescription orders at the dialysis unit early in the shift and give the prescription blanks to the patient. By the time the patient presented the prescriptions after dialysis (often after 4:30 pm) it was problematic to contact the prescribing physician regarding formulary and other therapy issues. Now all of the attending physicians are familiar with our formulary, and they often telephone in new prescriptions orders so that they can be filled and ready when the patient completes dialysis.

## Patient Benefits

Prior to pharmacist involvement at the dialysis unit, the dialysis patient usually never spoke to a pharmacist. They were often tired after treatment and waited outside in a vehicle while someone else picked up the medication. Now the pharmacist speaks with the patient on the unit during treatment (a captive audience, so to speak). The patient and pharmacist can spend as much time as it takes to review medication usage. Discussion includes determination of meal times, medication times, and the number of meals per day, all to help the patient determine the best timing of phosphate binder dosing. The patient is assured of receiving the current regimen of medications (filled off current medication orders instead of being refilled from what could be discontinued or changed medication orders). The patients no longer have to wait in the pharmacy for medications, and other patients don't have to wait while medications are filled for dialysis patients.

The patients at the dialysis unit have labs drawn monthly. These are reviewed with the patient by the dietitian or nutrition technician. If phosphate levels are high, discussions include the use of phosphate binders. If the albumin is low, patients are instructed to eat more lean meat. It was thought that before the pharmacist started bringing medications to the dialysis unit, many patients would go without their medications, including phosphate binders, if and when they ran out.

We compared average phosphate and calcium levels for patients who were on dialysis in 1998 (when there was no medication delivery) to levels in 1999 (after it was instituted). We also compared patients who received medications from GIMC to those who obtained them elsewhere. The normal phosphate level range is 3.5 - 5.5 mg/dl. While the average phosphate levels for all groups were in the normal range, the average phosphate level for the 33 patients who do not receive their medications at GIMC was 5.3 mg/dl in 1998 and 5.4 mg/dl in 1999 (an increase of 0.1 mg/dl). The average phosphate level for the 23 patients who do receive their medication from GIMC was 5.5 mg/dl in 1998 and 5.1 mg/dl in 1999 (a decrease of 0.4 mg/dl). All average calcium levels remained unchanged, possibly due to the fact that calcitriol injections are ordered for patients who become hypocalcemic.

While this is only anecdotal, nevertheless the physicians and dietitians believe that the GIMC patients were more compliant in taking their phosphate binders in 1999. The patients don't ever have to worry about running out since the medications are delivered to the dialysis unit on a regular basis. The pharmacist's interaction with the patients may also contribute to increased compliance and the decrease in phosphate levels, since the dietary consultation procedures remain unchanged.

## Dialysis Staff Benefits

The staff (social workers, dietitians, technicians, and nurses) at the RMCH Dialysis Unit now have a contact person to call when medication concerns occur. A physician, a dietitian, and a

social worker have all expressed written appreciation for the pharmacist involvement at the dialysis unit.

## Future Expansion

There are currently three pharmacists involved with the GIMC Pharmacy Nephrology Clinic. We would like to see additional pharmacists trained to rotate through the clinic. When pharmacy staffing permits, we would like to expand services to include the Peritoneal Dialysis Patient Care Conferences.

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