Regional Interagency Coordinating Committee (RICC)

Meeting Minutes

February 7th, 2005

12:00-3:00

Badland's Human Service Center

Attached Documents

2004-2005 QIP

12:00 – 1:00 New Business

Introductions

Members present:

Robin O., Gilda L., Tara B., Shonda W., Diane A., Wanda S., Dawn W., Jill S., Missi B., Cheryl A., Darcy H., Patty. Donna M., (Student Nurse), Laurie Hoffman (student nurse)

New Members

Wanda Schweiger (Parent)
Kim Feininger (Childcare Provider)
Diane Allen (Parent)

Removed Members

Dr. Kamille Sherman

Reimbursement Forms for Parents

Discussed new reimbursement form and rules

-All members are eligible for reimbursement

-According to federal regulations that govern Part C of the Individuals with Disabilities Education Act, members of the NDIC, RICC and their sub-committees or work groups who are ***unemployed*** or ***forfeited*** wages to participate in the advisory meetings are eligible to apply for a stipend. Stipends will be calculated based on a rate of $10 per half hour of the meeting and travel time, not to exceed $60 per day. To request a stipend, a stipend request form must be completed and attached to the Request for Reimbursement form.

Approval of October 18, 2004 minutes

We had the following questions for Debra Balsdon. She was not able to Polycom so we will save these questions for the next meeting.

Questions for Deb Balsdon (Administrator for Children and Family Supports – Developmental Disabilities Unit)

-How do we show action steps that have reached completion for the year, but are items that we do each year or that are ongoing.

-Opening Doors grants (specifically the handicap accessible swing).

Training Information

Family Connections Conference – June 8th, 9th, and 10th – Fargo ND

Reimbursements for expenses are available.

See the following website for more info:

www.conted.und.edu/connections/

K.I.D.S. Program Update

-Staffing/Evaluator Update

Fully staffed at this time, have had a huge influx of children from this summer to current. Staff is working and trained.

-Childcount Update

All childcount data has been included in the QIP (in the DATA portions of each target area)

-CAPTA Update/Policy

CAPTA referrals can now have the option to be screened by Right Track, Health Track or evaluated by KIDS program.

-Update on current numbers (referrals and evaluations)

The referrals haven't slowed down. There were 14 referrals in January.

Right Track Program Update

Jan-04 – 96
Feb-04 – 59
Mar-04 – 98
Apr-04 – 92
May-04 – 91

Jun-04 – 103
Jul-04 – 79
Aug-04 – 112
Sep-04 – 101
Oct-04 – 81
Nov-04 – 104
Dec-04 – 67
1083

Referrals to Right Track

13 – Baby Kind referral (St. Joseph's)
1 – Childcare
1 – Dr
1- Friend of parent
2 – KIDS program
5 – Parent Referrals
Others were not previously tracked

Kimm Sickler is headed back to the United States in the next week or so. She should be back to Dickinson soon.

Patty is currently collecting a list of "glitches" in the Right Track Data Base Program. She is reporting these to the state.

RICC Parent Subcommittee Update

-The Parent Subcommittee met on January 10th. We had five parents in attendance (Jessica K., Diane A., Wanda S., Dawn W., and Nichole T.,). Missi Baranko conducted the meeting. The committee spent some time reviewing the binders that new families receive at intake and comparing them to the binders that the families in Region 7 receive. Some suggested changes were made. We will continue to look at the impact the binders have on the families and how useful they are.

-The committee also discussed the Experienced Parent program and made some suggestions for the newsletter and possible new activities.

Experienced Parent Program Update

Held the following activities between November and January:

Craft Night
Transition Meeting

Play date at West River Community Center (playland)
Music and Movement Classes
Decorated Christmas Cookies
Swimming at the Community Center
Education on Infant and Toddler Brain Development

The following activities are coming up:
Making Valentine Cards
Education night on Temperament (given by Deb Theurer)
Music and Movement Classes
Play Date at WRCC (playland)
Sensory integration information (given by Darla – Rehab Visions)

Part C Data Update

In order to receive updated data for our QIP for each meeting we have changed our meeting dates to the following dates: February 7th, May 2nd, August 1st, and November 7th.

Sensory Integration Training

The Sensory Subcommittee met in November. Members of the committee are: Lori Pachl, Stacy Kilwein, Nichole Tooz, Diane Allen, Molly Traynor, Jill Staudinger, and Peg Crane.

The committee discussed the basics of hosting a Sensory Integration Conference in Dickinson. The committee agreed that the main goal is to educate the community (educators, parents, child care providers, foster parents, social services, etc) on Sensory Integration. The goals were as follows: What is it? - How does it affect kids? - Interventions and Strategies.

The committee also met on January 24th. We discussed who we would like as speakers. Nichole Tooz is in the process of contacting two gals who she highly recommended. Missi will send out further information via e-mail as soon as she receives it.

12:45-2:30 Quality Improvement Plan

Target Area: Childfind/Public Awareness

Review of Data: % of Infants and Toddlers receiving Early Intervention Services

- *National Target is 2%*
- ND (year) (7/1/03-6/30/04) 2.23%
- ND (day) (7/1/03-6/30/04) 2.23%
- Region VIII (Year) (as of 12/31/03) 4.34%
- Region VIII (Day) (as of 12/31/03) 4.34%

  Adams County (0%)
  Billings County (11.11%)
  Bowman County (2.25%)
  Dunn County (.88%)
  Golden Valley County (3.51%)
  Hettinger County (0%)
  Slope County (4.35%)
  Stark County (5.80%)
- ***Special Population Information (12/31/04)***
  - ***Native Americans (4)***
  - ***University Student Families (8)***
  - ***High School Program (1)***
  - ***Adoption (1)***
  - ***CAPTA (2)***
- Average Age of referral is 16.34 months (1/04-6/04)
  - ***13.3 Months (7/1/04-11/30/04)***

- ***Eligibility Information (7/04-12/04)***

Not Interested	***9***	***23.68%***
25/2	***19***	***50.00%***
Clinical Opinion	***3***	***7.89%***
Automatic	***4***	***10.53%***
50%	***1***	***2.63%***
Not eligible	***2***	***5.26%***

- Percent of referrals by category (as of 12/03)

  Referral Source:

  Families: 9 (17%)
  Right Track: 26 (50%)
  Social Services: 1 (2%)
  Physician: 10 (19%)
  Other: 5 (10%)

School: 1 (2%)
Total: 52

(7/1/04-12/31/04)

Referral Source		
Right Track	***27***	***52.94%***
Physician	***9***	***17.65%***
Parent	***3***	***5.88%***
Other	***1***	***1.96%***
CAPTA	***3***	***5.88%***
Interventionist	***2***	***3.92%***
Health Track	***2***	***3.92%***
Friend/Relative	***1***	***1.96%***
St. Alexius	***1***	***1.96%***
Medcenter	***1***	***1.96%***
County	***1***	***1.96%***

- ***Percentage of children being served in pre-school that were not identified before age three:***
  ECC/Headstart (1/15/05) (28%)
  (32 children on IEP, 23 from ID, 9 were screened at ECC)
  West River (1/15/05) (67%)
  (31 children on IEP, 10 from ID, 21 were screened at West River)

- Percent of children less than three that are screened thru Right Track
  We are still working at collecting and computing this data. It will be available at the meeting in May.

- ***Number of children screened thru Right Track to DDCM***

Jan-04 – 96
Feb-04 – 59
Mar-04 – 98
Apr-04 – 92
May-04 – 91
Jun-04 – 103
Jul-04 – 79
Aug-04 – 112
Sep-04 – 101
Oct-04 – 81
Nov-04 – 104
Dec-04 – 67
1083

(In 2003 there were 829 screenings)

- ***What are the referral sources to Right Track***

  13 – Baby Kind referral (St. Joseph's)
  1 – Childcare
  1 – Dr
  1- Friend of parent
  2 – KIDS program
  5 – Parent Referrals
  Others were not previously tracked

	ACTION STEP:	RESOURCES:	TIMELINE:	INDICATOR:

Concern: Earlier Identification (currently average age of referral in Region VIII is 16.34%) (13.3 % between 7/04-11/04) Right Track effectiveness is measured by average age of referral decreasing.

1C	Educate physicians on the benefits of early referrals.	KIDS DDCM RICC Members Experienced Parent	6/05	Right Track and KIDS will receive more referrals from physicians.

- Set up dates and schedule people to attend physician meetings to give presentations.
- Develop basic agenda for presentation.
- Dr. Oksa is Chief of Medical Staff.
- Jill, Kimm, and Merrill will work on setting up a time during a medical staff meeting.
- Make sure to include Bowman and Hettinger Staff
- Have Right Track releases/brochures presented at OB check and 2 week baby check up.
- Give Right Track presentation to BabyKind Staff (and brochures)
- Make sure that outlying counties are receiving the same information.

1D	Produce a simple reference sheet containing red flag behaviors of Autism for physician's to refer to.	KIDS RICC Coordinator Part C RICC Subcommittee	6/05	Physicians will be more aware of red flag behaviors of Autism and will refer these children to Right Track or KIDS at an earlier age.

- Schedule subcommittee meeting to put this together.
- Address the main areas to include in reference sheet.
- Below is an article referring to the early diagnose of autism.

- Have Merrill bring red flag list to May meeting for committee to review. The list will then be sent to physicians.

Beginning Monday, February 21 through February 25, NBC will air a 10-part, week-long series on autism spectrum disorders on the *Today Show*. Airtimes are 8:10 EST and 9:10 EST; Wednesday's segments will focus on intervention approaches, and, later each day that week, MSNBC will feature live interviews.

ASA professionals, including members of its National Board of Directors and Panel of Professional Advisors, as well as key ASA leaders President & CEO Lee Grossman and ASA Board Chair Cathy Pratt, Ph.D., are consulting with NBC producers as they develop story content.

The show plans to feature Donald Harvey, son of ASA Board Member Elaine Harvey. Harvey, who is a 38-year-old with autism, lives in Huntington, West Virginia and is one of several hundred clients of the Autism Services Center, a center founded 25 years ago by Ruth Christ Sullivan, Ph.D. In 1968, Sullivan became ASA's first elected president.

In addition, the CDC is scheduled to kick off of "Learn the Signs. Act Early," a major nationwide campaign designed to increase early diagnosis and early intervention for autism through the Centers for Disease Control and Prevention (CDC) and led by Director Julie Gerberding, M.D., M.P.H. Lee Grossman, along with Jose Cordero, M.D., M.P.H., Assistant Surgeon General and Director of the CDC's National Center on Birth Defects and Disabilities, are working closely together to mobilize autism community leaders to participate in this event.

In the upcoming weeks, ASA will reach out to local ASA chapters and encourages them to contact their local affiliate to do their own piece on autism in conjunction with the series. Stay posted to the ASA Web site as well as the February 15 issue of *ASA-Net* for further details.

The article below is from NYTimes.com

In Autism, New Goal Is Finding It Soon Enough to Fight It

December 14, 2004
By ANAHAD O'CONNOR

SEATTLE - Sitting in a small evaluation room at the University of Washington, apprehension written on her face, Christa Zamora turned her eyes toward her son Connor and contemplated his future.

A talkative and animated 2-year-old, Connor appears normal, Ms. Zamora said, but it is too soon to be certain. Doctors diagnosed autism in herolder son, Cameron, just before he turned 3. And with Connor, who is also at risk for developing the devastating neurological disorder, which runs in families, she has decided to be proactive, enrolling him in an early diagnosis study for children as young as 16 months.

"I'm very concerned," said Ms. Zamora, who is also worried about her third child, a boy due in February. "Connor seems to be past the danger zone. But Cameron repeats himself a lot, and sometimes I see Connor doing the very same things."

Across the country, thousands of toddlers like Connor are joining studies that could signal new hope for a baffling childhood disorder.

For years, autism was rarely noticed before the age of 2,its symptoms overlooked by busy parents or so subtle that pediatricians missed them. According to federal figures, only a third of the 6-year-olds who were receiving treatment for autism in 2002 had been identified by age 4.

But in the last two years much has changed. Propelled by an explosion of public awareness and growing evidence that early treatment with behavioral therapy can improve a child's chances, scientists have set out to diagnose the disorder as early as possible, and slowly, more children with autism are being identified before they turn 2.

Already, the average age of diagnosis in Britain has tumbled from roughly 43 months to 38 months or younger in only a few years, a pattern experts see emerging in the United States. And studies now under way could sharply alter the landscape of early detection by allowing physicians to routinely screen children before age 2,perhaps even in infancy.

"Part of it is that parents are more interested, and that pediatricians are getting a lot more sophisticated at detecting it," said Dr. Fred Volkmar, a professor of child psychiatry at Yale. "As these things have come together, there's no question we're seeing a lot more parents who are coming forward around the country with younger and younger children."

Autism isolates, robbing those afflicted of their ability to communicate or to grasp even basic social cues. Human faces, awash in meaning to most people, are inscrutable to people with autism; many cannot look another person in the eye. But behavioral therapy is one bridge to the outside world, and while experts say it can make a difference at any age, almost all agree that it has the largest effect on a child's language, social development and I.Q. when started before children turn 4.

"Intervention should start before the age of 3, and certainly by the age of 4," said Dr. Deborah Fein, a professor of psychology at the University of Connecticut. "After a certain point, you can still teach an autistic child certain things, ameliorate destructive behaviors, but you're not really going to change the developmental pathway that they're on."

The goal now, experts say, is to augment screening techniques so cases no longer elude them as the window for intervention narrows.

At the University of Washington and elsewhere, researchers are experimenting with a routine test that can flag children by 18 months, the earliest point for reliably identifying the disorder, many experts contend. It is also early enough for therapists to intervene.

At the same time, other researchers see promise in more sophisticated diagnostic tools - devices that can measure brain and behavioral responses to the sound of a mother's voice, or genetic or biological markers that can be detected in infancy.

"The goal is to be able to identify these kids at birth," said Dr. Geraldine Dawson, director of the University of Washington's autism center. "Until fairly recently, we hadn't really defined the very early symptoms of autism. But in the last several years, research has identified the behaviors you can see in a child as young as 12 months."

Dr. Dawson and others hope to accelerate their progress by focusing on high-risk groups. About one person in 200 in the general population suffers from autism spectrum disorder, compared with roughly one person in 20 who has an autistic older brother or sister.

As a result, researchers are increasingly focusing on the families of autistic children, recruiting younger siblings who can be followed from birth to pinpoint when normal development veers off course.

Such studies could help scientists learn, among other things, why roughly a quarter of children with the disorder descend into autism seemingly overnight, quickly spiraling from talkative to mute, outgoing to aloof. In the past, when diagnoses were made after age 4 or 5, scientists were forced to rely on grainy home videos of first birthdays for early clues. Now, they are seeing autism unfold before their eyes.

"We're hoping that if we follow enough kids, we can watch that progression," said Dr. Catherine Lord, director of the autism and communication disorders program at the University of Michigan.

Faint Signs Often Missed

In some cases, researchers are already reporting breakthroughs. Last month, Dr. Ami Klin, an associate professor

of child psychology and psychiatry at Yale, published one of the most comprehensive case reports of a toddler with autism. The child, called Helen by Dr. Klin in the article to protect her identity, was 15 months old when autism was diagnosed. At 12 months, her language skills deteriorated and she began withdrawing. By the time she reached the clinic, she had almost no interest in other people. Her brother, two years older, is also autistic.

"Historically, children wouldn't reach a specialized center like ours until a much later stage," Dr. Klin said.

Experts say that while more and more children like Helen are coming to their attention, for now, they are the exception. It is too soon, many agree, for most children that young to be spotted by anyone other than a specialist or an alert parent who has already raised an autistic child.

At that age, the range of social behaviors is limited, and most tests were developed for older children, intended to see if a child was engaging in age-appropriate activities like playing peek-a-boo or showing interest in other children. The signs of autism may be too faint to show up in such tests, or simply not yet present.

"One big problem is that some kids just don't have all the features by 2 or 3," Dr. Volkmar said.

Chances Slip Away

Another problem, even with older children, is that pediatricians rarely use the tests, which can take time to administer, to screen their young patients. Instead, one study by the American Academy of Pediatrics found, most physicians prefer to "eyeball" children, a notoriously unreliable method that probably allows many cases to go unnoticed.

Other doctors sidestep the issue altogether. Parents who express concerns about their toddlers are often told to wait a few months, "to see if the child grows out of it." Rather than make the fateful decision to refer a child to a specialist for a diagnosis, some experts say, pediatricians sometimes suggest instead that the children are late talkers, or only slightly behind.

"I think a lot of doctors, if they aren't completely sure about what they are seeing, are afraid to say so," said Dr. Isabelle Rapin, a professor of child neurology at the Children's Hospital at Montefiore in the Bronx. "So they tell the parent 'you're overworried,' or they come up with all sorts of excuses because they don't want to give a parent the news that their child might be autistic."

But delaying a diagnosis, and as a result early treatment, can have lifelong consequences. A child referred to a specialist can end up on a waiting list for months in some parts of the United States. When the diagnosis finally comes, another year could go by while the child waits on a second list for treatment.

"The journey is easily over two years from the first step to getting treatment," Dr. Dawson said.

All the while, chances to slow the progression of the disorder slip away. To encourage parents and physicians to act quickly when a child's development is stagnating, experts at the Centers for Disease Control and Prevention, working with other groups, have begun a public awareness campaign, called "Learn the Signs. Act Early."

It is designed to educate parents and health care professionals about the major milestones, from imitating facial expressions to finger-pointing and telling stories, that a child needs to achieve at various developmental points between 3 months and 5 years.

Casting a Wide Net

And who better to spot autism than parents? Subtle changes in behavior may be more obvious to a mother or father who sees a child daily than to a pediatrician who has 50 other patients.

So experts want parents to play a larger role. They have taken a widely used screening tool, the Checklist for Autism in Toddlers, or the CHAT, and replaced a section that pediatricians complete with a series of yes-or-no questions for parents. It can be filled out in just a few minutes, ideally at home or in a waiting room before a child's checkup. It is available online at firstsigns.org.

Unlike its earlier version, which is extremely precise, the new M-CHAT casts a wide net. In England, studies of

thousands of children showed that the CHAT, although it accurately identified many cases of autism, was so specific that it failed to detect a majority of cases. The M-CHAT, with looser boundaries and greater sensitivity, is intended to flag even subtle cases. Experts say that it will probably produce more false positives - flagging children who are not actually autistic - but that they prefer to err on the side of caution.

Dr. Fein, of Connecticut, is leading a large study to help validate the M-CHAT's usefulness. In the last five years, about 4,000 New England toddlers, ages 18 months to 24 months, have been screened with the test during normal visits to their pediatricians. At the age of 4, they are evaluated once more to determine whether the M-CHAT is accurate. So far, Dr. Fein said, autism has been diagnosed in about 200 cases, and the test is holding up.

"Most of the kids stay with their diagnosis," she said. "If we didn't think they were autistic at 2, then they aren't autistic at 4."

On the other hand, about 15 to 20 percent of the children labeled autistic at 2 no longer meet the definition by the time they turn 4. That could mean that they were false positives, Dr. Fein said, or simply that catching them early made a difference.

"One possibility is that they got good, effective intervention and recovered, which I think is what's really going on," she said. "I see a lot of kids at 2 who are clearly autistic and then at 4 they are doing terrific. These are kids who have recovered enough so that no one would ever know that they were on the autistic spectrum."

Such outcomes, Dr. Fein said, are rare but not impossible. Many more children who begin behavioral therapies will make more modest gains, improving just enough to grasp a few rules of social interaction, or building a small vocabulary. Still others will remain severely disabled, beyond the reach of any therapy. Dr. Eric Fombonne at McGill University in Montreal, for one, says that some children cannot completely overcome autism.

He points to studies suggesting that children who show marked improvement after behavioral intervention are those labeled P.D.D.-N.O.S., or pervasive developmental disorder not otherwise specified, because they exhibit only some autistic symptoms. Those who meet the stricter definition of autism often show less impressive results.

"Some children, at base line, have more severe difficulties and won't always make the expected gains," said Dr. Fombonne, a professor of child and adolescent psychiatry.

The extent of behavioral therapy's potential remains an open question, and evidence suggests that it varies enormously from one child to the next. Yet even those who believe it has only limited effect on some children seem to agree, nonetheless, that it is most helpful when started early.

"What we do know is if you start it after a certain age, the outcome is going to be more negative," said Dr. Fombonne. "It makes sense that that would be the case."

In the coming years, some advocates hope, every child will be screened for autism by his or her second birthday, with the M-CHAT or a similar checklist. But casually observing a small child's behavior only reveals so much, and researchers say they will need more diagnostic tools if they are to detect faint glimmers of the disorder in infants.

A Mother's Melody

Dr. Patricia Kuhl and colleagues at the University of Washington think they have one answer. They have found that small children are naturally lured by the melody of amother's speech - the stretched pronunciation of vowels that produces sounds like "ah" and "oo." When exposed to this baby talk, or "motherese," normally developing children display a distinct pattern of brain activity that can be measured with electrodes, while autistic children show little interest and fail to produce the expected neural response. Autistic subjects, on average, prefer to listen to a computer generated warble instead.

The findings suggest that autistic brains may be wired differently from birth, leading to delays in language and other hallmarks of the disorder.
"The beauty from a practical aspect is that these simple measures can be used extremely early in life," Dr. Kuhl said.

Perhaps the simplest autism screening tool, one that many consider the holy grail of early detection research, is a genetic test. It is not clear to what extent environmental influences - infections and childhood vaccines, for example - play a role in the onset of the disorder, but experts are certain that heredity is a major factor. Studies of identical twins, for example, suggest that if one twin has autism then the other has more than a 60 percent chance of being autistic as well.

After years of searching, they have homed in on several regions of different chromosomes that may lie behind autism, and earlier this year a team at the Mount Sinai School of Medicine in New York pinpointed at least one gene that contributes to the disorder. A simple genetic test, however, is more elusive than it seems. Experts suspect that more than 20 genes could be involved, each underlying a different aspect of autism. Dr. Dawson, in her studies of high-risk siblings, is finding that even children who inherit just a few of these genes, like Connor Zamora in Seattle, may periodically display repetitive movements or other quirky behaviors without actually crossing the threshold into full-blown autism. About 10 to 15 percent of siblings may have this milder variant, Dr. Dawson said.

"It's a new concept for parents to understand," she said. "They could have a young child who doesn't have enough symptoms to have autism, but has some mild aspects like language delay or social awkwardness that they might need help with."

Experts say that for all the promise it might hold, a screening technique that can consistently detect children younger than 18 months, not to mention in infancy, is probably years away. To the extent that that is even possible, scientists say they would then have to grapple with a much larger problem: providing treatment to an explosion of small children when services are already stretched thin.

"We're going to have more and more children under 3 getting diagnosed," said Dr. Volkmar. "But sadly, it looks like we're going to have fewer and fewer services for them."

1F	Provide Norm Reference Materials (create poster/flyer) to all Child Care Facilities, Churches, Doctor's Offices, WIC, etc.	KIDS RICC Coordinator RICC Committee Members (Denise S., Jessica K., Nichole T.,) Early Head Start (Cheryl) West River Special Service (Robin) Funding: Part B (Dot and Terry Tucker), Part C	Development – 9/30/04	Right Track and KIDS will receive more referrals from parents, child care providers, physicians, and family members of children.

- Distribute posters from the State (when we receive them).
- Produce simple flyer/brochure with developmental age appropriates.
- Set up subcommittee to go over previous developmental age appropriates.
- **The brochures have been made and are currently being distributed by KIDS and Right Track.**
- **Begin providing brochures to all Family Physicians and Pediatricians for them to hand out at Well Child Visits. Missi suggested that they be handed out at all visits done by 0-3 year olds.**
- **It was also suggested that the brochures be handed out to all county health nurses.**

- **Missi will contact the administrators at Great Plains Clinic and Dickinson Clinics.**

Concern: There are children who are receiving and/or referred direct therapy that are not referred for Early Intervention.

1G	Provide outpatient therapy agencies with information regarding Right Rack and Early Intervention Services	KIDS, RICC Coordinator	6/05	Right Track and KIDS will receive referrals from direct therapy service providers.

- Need to visit with Outpatient therapy and staff.
- Make sure to include SW Physical Therapy.
- **Provide Developmental Brochures to all Outpatient Therapy Services.**

Concern: Parents feel physicians are not aware of all of the options available for children with developmental needs.

1H	Educate medical community on Applied Behavior Analysis team approach for children with Autism Spectrum Disorder. Set up a panel of doctors from both clinics, surrounding areas, and family members to explain ABA and the availability of it.	KIDS Program Merrill F., Dr. O'hara, RICC Coordinator	9/1/04 6/05	The medical community will be more aware of options available to children with Autism.

- Review information received from Kristi Hintz on training by Lynn Hamilton (www.facingautism.com) before setting up a panel of doctors.
- Lynn Hamilton has been contacted and she is interested in coming to Dickinson to do a training on Applied Behavior Analysis. She discusses therapy, early intervention, and other related topics. She charges $1000 to speak at a conference for the day.
- She speaks from a parents perspective. We are not sure if we will still be able to get her as she is currently pregnant.
- **An Autism Support group has been started by Cathy Quintane and Angela Cavett.**

Concern: Percentage of children involved in Early Intervention is generally smaller in special populations and rural areas.

1K	Get birth data for each county to cross reference the children that are being screened and the children that are being referred.	RICC Coordinator Right Track KIDS	11/1/04	Percent of referrals in rural areas will increase.

- **Right Track is currently working on gathering the screening data for each region. This data will be cross referenced with birth data to**

come up with an accurate percentage of children being screened in each county.

The committee reviewed the "Places to Call" sheet. The information listed common places that parents might contact if concerned about their child's development. Missi contacted all of these places and "played" a mother concerned about her two year olds speech. The responses varied from each agency.

Target Area: EI Services in Natural Environments

- Percent of outcomes associated with Early Intervention Services that were achieved or progress was made.
- Percent of Home Visits Completed.

December 2003	51%
January 2004	68%
February 2004	66%
March 2004	69%
April 2004	61%
May 2004	66%
June 2004	72%

TOTALS	TOTALS	%
V = VISIT MADE	443	62%
E = EVAL	6	1%
C = CONSULT	1	2%
M = MEETING	29	4%
TOTALS		**69%**
H = HOLIDAY	11	0%
W = WEATHER	6	1%
NC = NO CONTACT	25	4%
NS = NO SHOW	5	1%
F1 = FAMILY ILL	35	5%
F2 = FAMILY VACATION	17	2%
F3 = FAMILY - SCHEDULE CONFLICT	22	3%
F4 = FAMILY NO REASON GIVEN	9	1%
F5 = FAMILY MISC	30	4%
I1 = INTERVENTIONIST ILL	19	3%
I2 = INTERVENTIONIST VACATION	18	3%
I3 = INTERVENTIONIST SCHEDULE CONFLICT	20	3%
I4 = INTERVENTIONIST MEETING - NOT WITH FAMILY	7	1%
I5 = INTERVENTIONIST TRAINING	10	1%
T = TRANSITIONED OUT OF PROGRAM	0	0%
N = NO VISIT DUE FOR DAY/WEEK	46	

Personnel PT/OT/SLP/Vision/Hearing/AT/Medical Specialties (12/31/04) (total of 164)

Assistive technology services/devices (20)
Audiology (4)
Family training, counseling, home visits, and other support (68)
Health services (0)
Medical services (for diagnostic or evaluation purposes) (12)
Nursing services (0)
Nutrition services (21)
Occupational services (4)
Physical therapy (4)
Psychological services (0)
Respite care (0)
Social work services (0)
Special instruction (13)
Speech-language pathology (10)
Transportation and related cost (2)
Vision services (4)
Parent/infant program thru the NDSD or NDSB (2)
Other early intervention services * (0)

- As of 12/03 serving 6 out of 8 counties
  Bowman, Billings, Dunn, Golden Valley, Slope, and Stark
- 6 month review for IFSP's
  12/03-9/15/04
  40 Six-Month Reviews Held
    31 were not held by the 6 month date
    8 were held by the 6 month date
    Out of the 31 not held by 6 month date, 18 were held during the 6th month
    Out of the 31 not held by 6 month date, 6 were held within the 7th month

- Part C funding and Medical Assistance is now available for children and their families. Since this availability for families we do not see unmet needs for family subsidy.
- Multi disciplinary evaluations are used for all evals.
- Natural Learning Opportunities are incorporated into a child's IFSP.
- Availability of Childcare
- Parent Satisfaction with Service Coordination
  Overall, on the Parent Evaluations from 2004, families are satisfied with all aspects of Infant Development.
- ***Amount of Infant Development Services, Location and Times (as of 1/1/05)***
  Amount: 70 total, 67.75 Actual Seen, 65.75 total billable
    1 time per month: 3
    2 times per month: 4
    1 time per week: 60

2 times per week: 3

Location: Many locations are offered (daycare, home, park, etc)
Times: Visits occur at optimal times for families and their child at their choice of time.

- Services received or needed are listed on Case Plan.
- Training Opportunities are presented to the region. All training interests are run through grant proposals.

	ACTION STEP:	RESOURCES:	TIMELINE:	INDICATOR:

Concern: Most of the parks in the region have handicap accessibility issues.

2A	Contact the Park Board to inform of accessibility issues and need for fencing for existing playgrounds. Apply for Opening Doors Grant to add 15 handicap accessible swings to the regions parks.	Parent members of committee, RICC Coordinator, Experienced Parent	10/31/2001 (Completed) Update about Part C Funds 8/1/04	Families that have children with developmental delays or disabilities will be accessing the parks more often.

- Find durable handicap accessible swing, write, and submit grant.
- **The grant was resubmitted in August 2004 with changes made. We have not heard back from Deb Balsdon on the progress of this grant.**

Concern: Shopping can be very difficult for families with young children that have developmental delays or disabilities.

2B	Submit Opening Doors grant for child friendly, handicap accessible shopping carts	RICC Coordinator	8/15/04	Families that have children with developmental delays or disabilities will be able to have a more safe and enjoyable shopping experience.

- Find durable handicap accessible shopping cart, write, and submit grant.
- **The grant was submitted in June 2004. It was denied with suggested changes to be made. We are currently waiting for the Opening Doors grant to be re-RFP'ed**

Concern: Children with developmental delays or disabilities do not have appropriate swimming classes to attend.

2C	Submit Opening Doors grant to provide training materials and equipment that support inclusion of children with developmental delays or disabilities to WRCC and Dickinson Park and Rec swimming lessons.	RICC Coordinator	8/15/04	Families that have children with developmental delays or disabilities will be able to participate in the swimming classes offered by Dickinson Park and Recreation.

- Contact other programs across the state to find out what equipment they use to support the inclusion of children with developmental delays or disabilities.
- Research the internet to find equipment, training, and videos.
- Contact Dickinson Park and Rec staff to explain grant and get ideas from them.
- Write and submit grant.
- **The grant was submitted in June 2004. It was denied with suggested changes to be made. We are currently waiting for the Opening Doors grant to be re-RFP'ed**

Concern: Dickinson Park and Recreation Center is unaware of changes that could be made to help to support the inclusion of children with developmental delays or disabilities.

2E	Set up a committee with Park and Rec to help to advise on the needs of children with developmental delays or disabilities.	RICC Coordinator Experienced Parent Public RICC committee members	1/1/05	Families that have children with developmental delays or disabilities will be able to participate in all activities sponsored by Park and Rec.

- Contact other programs across the state to find out what equipment they use to support the inclusion of children with developmental delays or disabilities.
- Research the internet to find equipment, training, and videos.
- **We are currently waiting for the Opening Doors grant to be re-RFP'ed**
- **A committee has been set up with Park and Rec. This committee contains members from the RICC and community. Some members include parents, teachers, OT's, PT',s and Park and Rec Staff.**
- **Send Dickinson Park and Rec a Thank You Card.**

Concern: Percentage of completed home visits is less than 75%. The reasons are not currently collected.

2F	Break down data will be provided to more accurately determine reasons for visits not being completed.	KIDS	1/1/05	Families will be having more visits. We will be more aware of the reasons visits are canceled

- **Data is currently being broken down and recorded.**

2G	Add the following question to the annual questionnaire: When a visit needs to be canceled, are you offered another time/date?	KIDS	1/1/05	Families will be having more visits. We will be more aware of the reasons visits are canceled

- The question has been added to the annual questionnaire.

Target Area: Family Centered System of Services

Review of Data

- Average days from referral to IFSP completion (1/04-8/1/04)
  46.22 days
  0(0-25) 7(26-35) 10(36-45) 13(46-75) 0(75-100) 1(101- above)

  Average days from referral to IFSP completion (7/04-11/30/04)
  49.56 days
  0(0-25) 4(26-35) 2(36-45) 18(46-75) 1(75-100) 0(101- above)

- Percent of children found eligible and had an IFSP developed within 45 days from date of referral (1/1/04-8/1/04) 47 referrals (31 enrolled)
  children out of 31 (84%)
  (7/1/04-12/31/04) 23 enrolled (13.33% had IFSP written within 45 days)
- All families sign a form stating that they are involved in the development of the outcomes for their child.
- Families are given the option to be involved in eligibility meetings.
- Families are part of the evaluation/assessment process.
- All meetings pertaining to a child are scheduled at a families choice of dates/times/locations.
- All families currently in Infant Development are fluent in English.
- Currently there is no need for material to be available in alternative formats and/or languages.
- Families are informed that they have a choice of DDCM and ID Staff.
- ***Ineligible children are provided with resources on development for parents to utilize.***

	ACTION STEP:	RESOURCES:	TIMELINE:	INDICATOR:

Concern: The intake process can seem unfamiliar and overwhelming.

3A	Refine intake process and implement procedures to minimize family intrusiveness and reduce time between referral and service delivery by adding materials, resources and developmental age appropriates to the Binder families receive during the enrollment process.	DDCM EI Video Age Appropriate Checklists Experienced Parent	5/31/04	We will meet federal requirements of 45 days from referral to IFSP while still being family friendly. Families will also be provided with family friendly material.

- Set up subcommittee to redo Developmental Age Appropriate Material.
- Include this new material in the binder that families receive at intake.
- Have the Experienced Parent contact all families after intake.
- **Parent Subcommittee is reviewing the intake binders.**

Concern: Service Providers and community have a lack of understanding of Sensory Integration.

3D	Educate and provide the community opportunities on benefits on how Sensory Integration impacts daily life and experiences. Pair up Community Members with a panel of Providers at training. Incorporate Parents into the training.	Parent Resource Center (Stacy Kilwein) IDEA Part C Part B DSU Extended Campus (Marty Odermann Gardner) Nichole Tooz	October Meeting to discuss training opportunities 8/1/05	The community will have a better understanding on the benefits and impact of sensory integration.

- RICC Members will be attending a Sensory Integration Seminar in Fargo in September. After the seminar, at the October meeting, we will discuss how we want to educate the community on Sensory Integration.
- **A Sensory Subcommittee has been formed. The committee is currently working on providing a Sensory Integration conference in our community.**

Target Area: Early Childhood Transition

Review of Data:

- ***Number of children that transition annually (12/1/03-11/30/04)***
  48 families
  No response: 6
  Withdrawal by parent (not at age level): 2
  Withdrawal by parent (at age level): 4
  Moved: 8
  Not Eligible to part B – exit to other programs: 2
  Not Eligible to part B – exit with no referrals: 1

Part B Eligibility not determined: 1
Part B Eligibility not determined due to parent: 3
Part B Eligible: 21

- ***Percent of children that are eligible for early childhood special education services. (12/1/03-11/30/04) (46%)***

- Percent of families that had Transition Outcomes in the IFSP by the time the child was 2 years of age.
- Percentage of families that request that DD Case Management Services continue after the child turned three.
- Percentage of IFSP's that continued to be used after the child was three years old.
- The majority of children transitioning into a public preschool program use an updated IFSP for the first few months until an IEP is written.

	ACTION STEP:	RESOURCES:	TIMELINE:	INDICATOR:

Concern: Parents have not always understood the transition process, parental rights, and the support necessary to exercise those rights.

4A	Utilize State Transition Book	State	9/31/04	Parents will be more informed about the transition process.

- **Jill will update on the State Transition Book.**
- **With new possible federal regulations coming thru from IDEA, the transition book has been put on hold until those changes have been made. (staying in the program between the ages of 3-5)**

Concern: Parents and team members are unaware of services in the summer for children who do not qualify for extended school services or Part B preschool programs.

4D	Clarify "Summer Services for 3 year olds" Memo and identify chosen option for services.	ECC West River KIDS	8/1/04	Parents who have children who transition in the summer will be more educated on developmentally appropriate activities

- **Jill will update on possible changes for summer transitions and Memo.**

- **Early Intervention Programs told to "throw the memo out" and since there is now a subcommittee group re-looking at the issues – the guidelines are being looked at and we will go from there.**

Concern: Parents and team members are unaware of services in the summer for children who do not qualify for extended school services or Part B preschool programs.

4E	Upon parents request or if appropriate, parents will be given educational materials for families to work on during the summer.	Early Childhood Center	8/1/04	Parents who have children who transition in the summer will be more educated on developmentally appropriate activities

Concern: Parents state that they are concerned about lack of programming for their children

4F	ECC Staff will contact transitioning families at least once during the summer.	ECC	8/1/04	Families are supported and informed of programming and rights.

4G	Parents of children attending ECC will be made aware and have a home visit from the child's assigned teacher before school Starts.	ECC	9/1/04	Parents and children are informed and prepared for the transition process. The classroom teacher and case manager will do the home visit

4H	Parents of children attending West River Special Services will be contacted as soon as the educational arrangements have been made.	West River Special Services	9/1/04	Parents and children are informed and prepared for the transition process.

Concern: Parents are not aware of the possible categories that their children may receive at the IEP.

4K	Inform parents of categories of eligibility at the 2-6 meetings.	KIDS ECC West River Special Services	8/1/04	Parents will be educated about categories and that their child will be labeled.

- **Set up meeting to discuss guidelines on how to present eligibility criteria for 619 services. Include parents, interventionists, ECC and WR staff and DD Case Management.**

Concern: Eligibility for age 3 school services is slowed when standardized procedures are not followed.

4L	Evaluation will be done in one session when completed at outpatient therapy, not over two or three sessions.	KIDS Interventionists	7/31/04	Standardized protocol will determine age 3 eligibility.

- **Look at evaluation options. Standard scores will be interpreted. Set up training for all agencies/evaluators who are involved in KIDS Program Evaluations.**
- **Set up training "reminder" for evaluators determining eligibility.**

Concern: Agencies in Region 8 do not have a history of joint assessment.

4O	Educate agencies on the Memorandum of understanding between DPI and Part C	KIDS ECC West River Multi district Special Education Unit	11/1/04	School agencies will participate in Joint Assessment when deemed necessary.

- **Jill will updated on the 1995 Memo. The State Transition Committee is addressing concern.**

2:30-3:00 Old Business/Open Discussion