

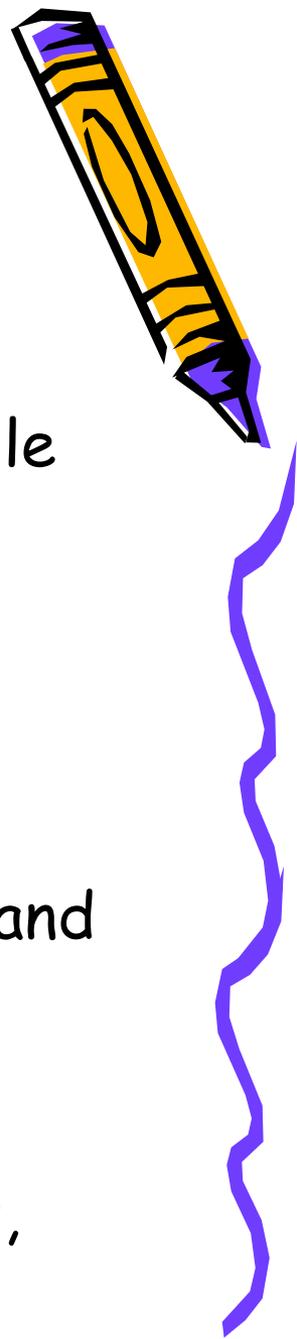
Missed Opportunities: Early Intervention

Why and How It Makes A
Difference in the Lives
of At-Risk Children



Maura McInerney, JD
Education Law Center

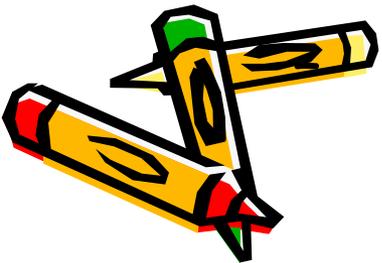
Legal Center for Foster Care & Education

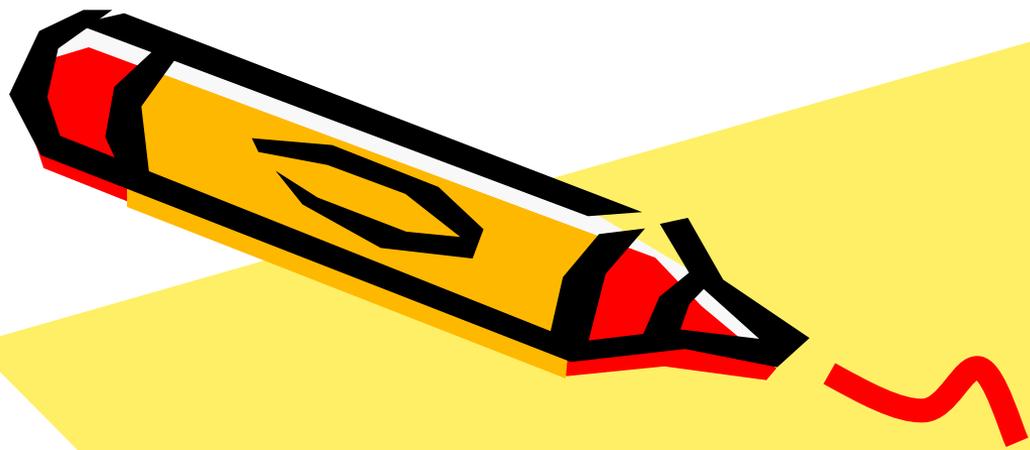


- A collaboration between the ABA, the Juvenile Law Center and Education Law Center, Casey Family Programs and the Annie E. Casey Foundation.
- A national technical assistance resource and information clearinghouse on legal and policy matters affecting the education of children and youth in out-of-home care

- Website: www.abanet.org/child/education

Listserv, Conference Calls, Publications,
Searchable Database





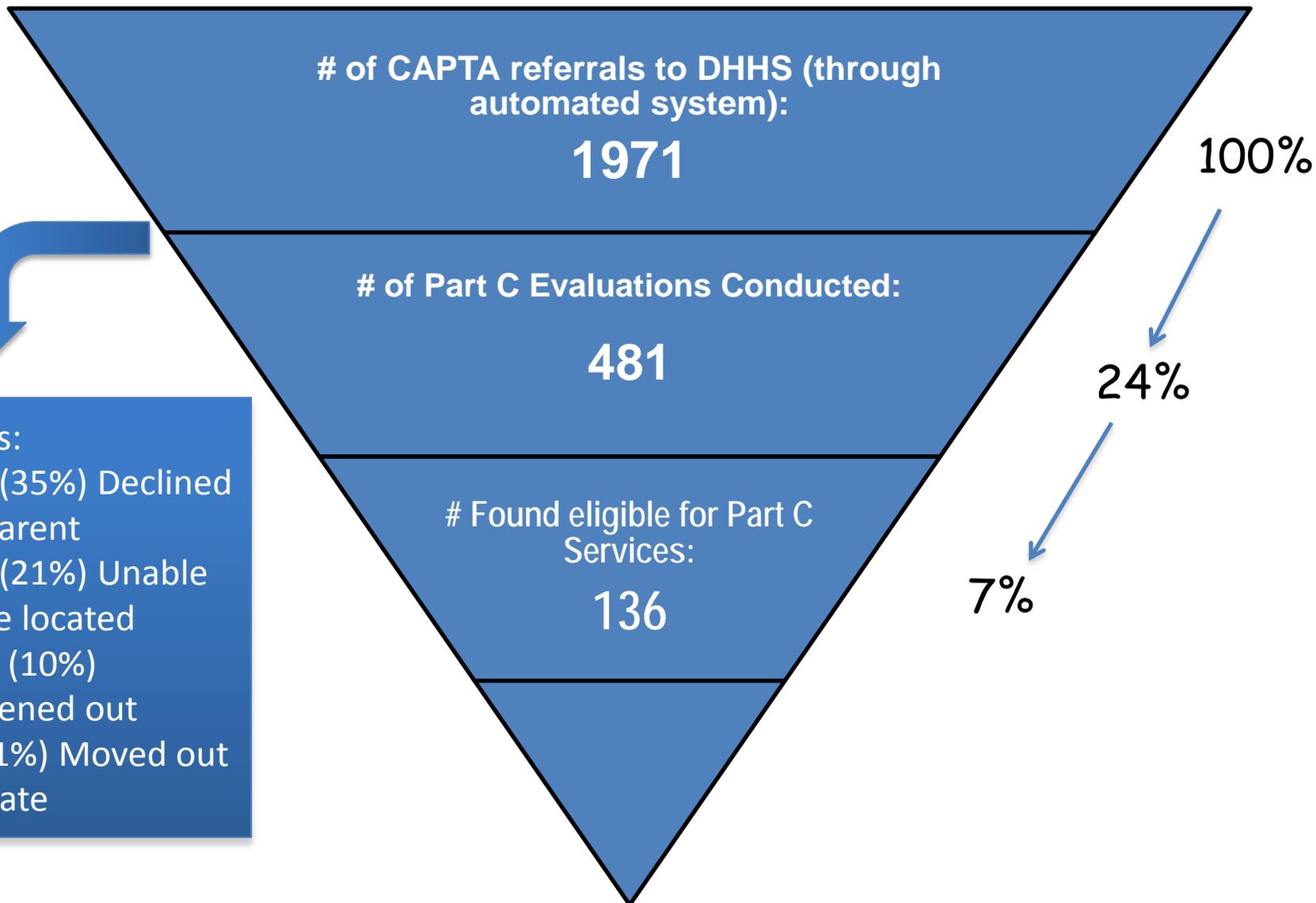
Two children's stories...



Nebraska Part C CAPTA Evaluations and Services

DROP OFF ANALYSIS

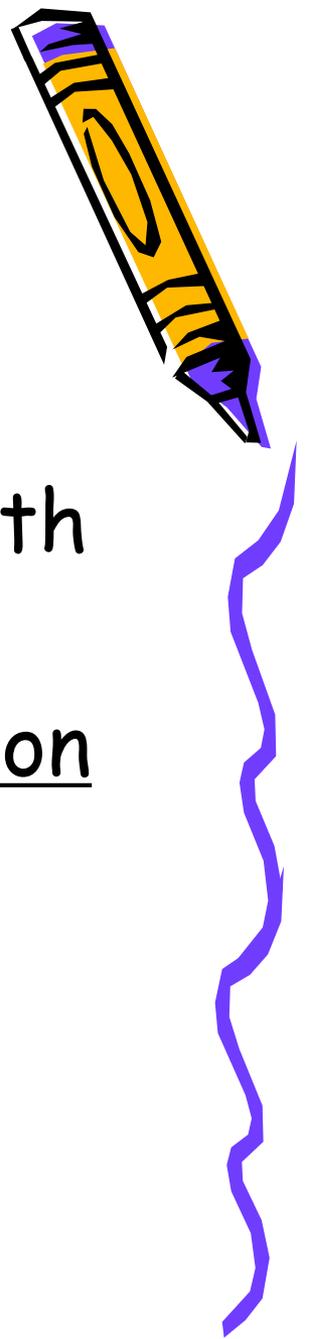
1-1-11 to 12-31-11



Reasons:

- ✓ 696 (35%) Declined by parent
- ✓ 411 (21%) Unable to be located
- ✓ 203 (10%) Screened out
- ✓ 23 (1%) Moved out of state

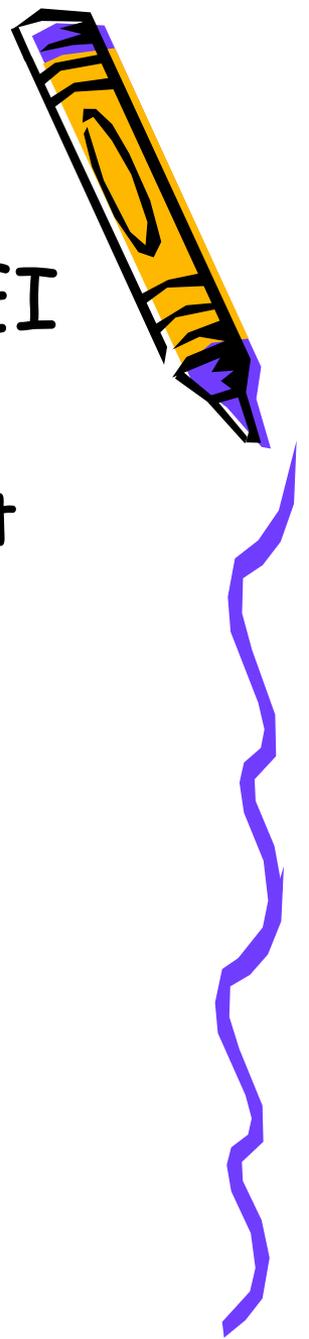
Background



- 1975 P.L. 94-142 Education for All Handicapped Children's Act-
- Reauthorized as the Individuals with Disabilities Education Act (IDEA)
- Followed by explosion of research on infancy & early child development
 - 0-3 Rapid brain & CNS development
 - Early brain plasticity



Background--

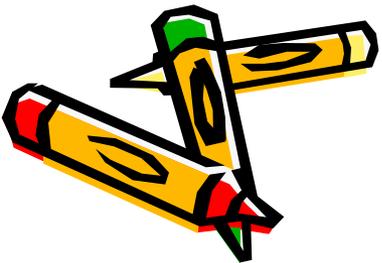


- Research on “infant stimulation” -EI
 - Abecedarian Project-Ramey
 - Infant Health & Development Project
- 1986 P.L. 99-457 IDEA Reauthorization
 - Encouraged states to develop 0-3 services for infants/toddlers with disabilities
 - Passed as prevention method



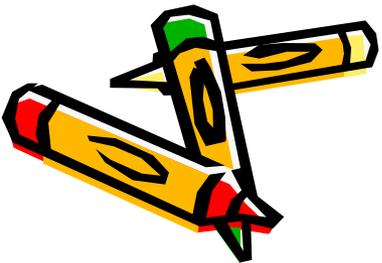
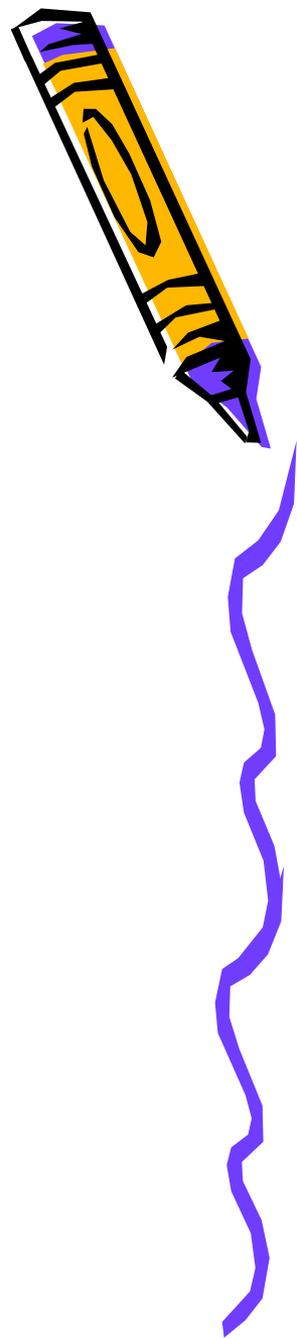
Early Intervention Defined

- Services, education and support to children ages birth to five who
 - have an existing delay;
 - a physical or mental condition with a “high probability” of a developmental delay; or
 - are “at-risk” of developing a delay or special need that may affect their development or impede their education.

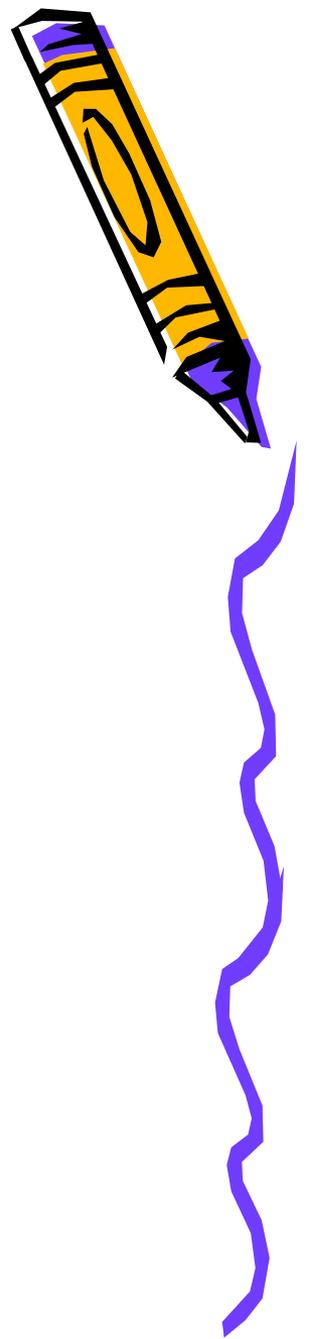


Types of services

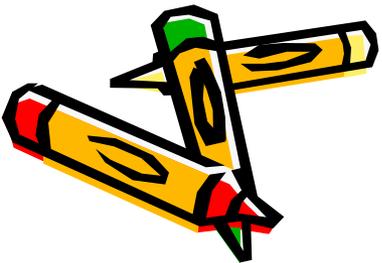
- Directly impact child:
 - Structured experiences
 - Developmental therapies
 - Instruction
- Indirectly impact child by working with caregiver:
 - Information
 - Instruction
 - Emotional Support
 - Help accessing additional resources



Why “Early”?

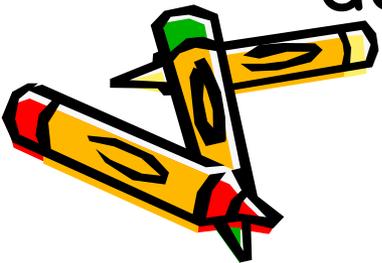
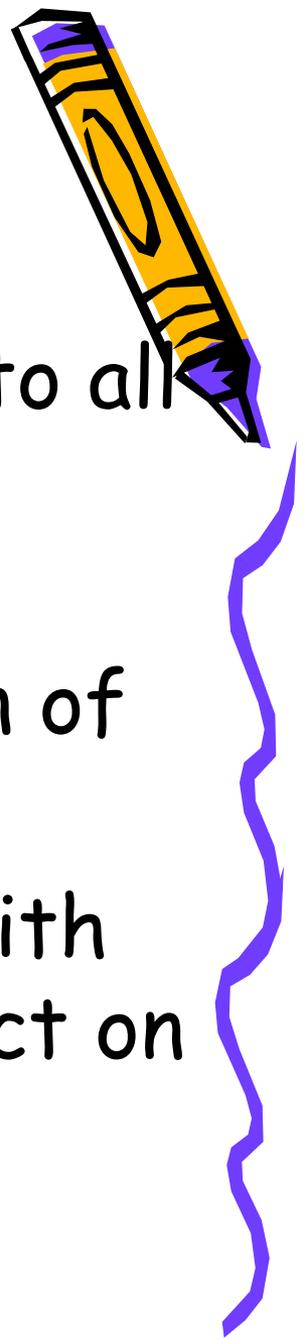


- Rate of human learning and development is most rapid.
- Timing of intervention is critical because a child runs the risk of “missing” opportunities to learn.

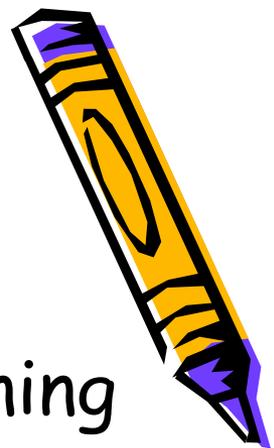


Theories of Change

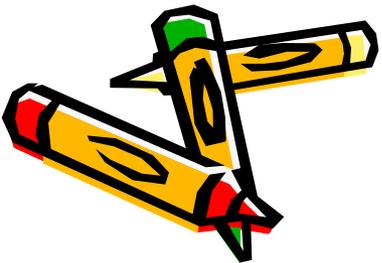
- Principles of development apply to all children regardless of biological variability and life experiences
- Development involves interaction of genetic and experiential factors
- Young children's relationships with primary caregivers = major impact on development



Purpose of “EI”



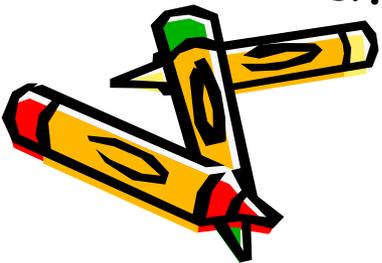
- Increase child's opportunities for learning
- Lessen effects of a disability or delay
 - physical, cognitive, communication, social or emotional, and adaptive development.
- Improve functioning of families
- Increase long-term benefits for society



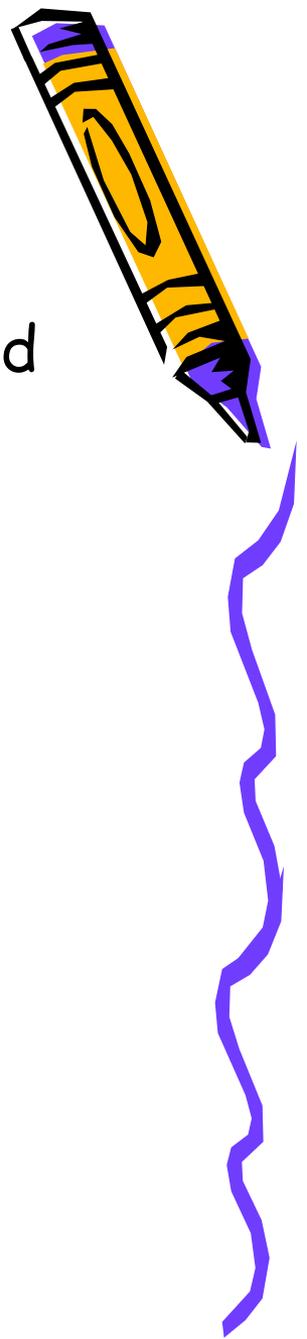
Why “Intervene”?

It works.

- Increases developmental and educational gains for the child
- Results in the child:
 - (a) needing fewer special education and other rehabilitative services
 - (b) being retained in grade less often;
 - (c) in some cases being indistinguishable from non-handicapped classmates years after intervention.

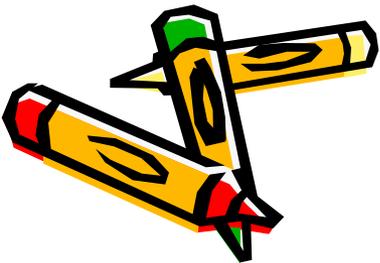


Research: Benefits of Early Intervention

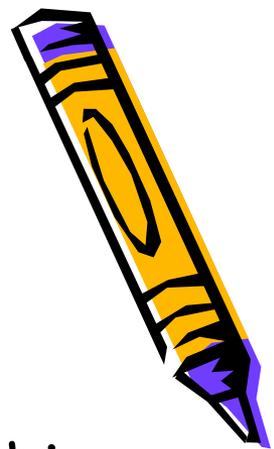


- Higher levels of school readiness, standardized test scores and future academic attainment
- Lower rates of grade retention
- Lower rates of special ed placement
- Higher parent participation
- Lower juvenile delinquency rates

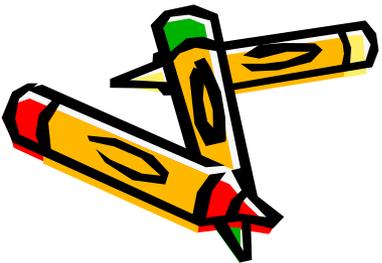
(Campbell, Ramey, Pungello, Sparling, & Miller-Johnson, 2003; Reynolds, Temple, Robertson, & Mann, 2001; Reynolds, Ou, Topitzes, 2004).



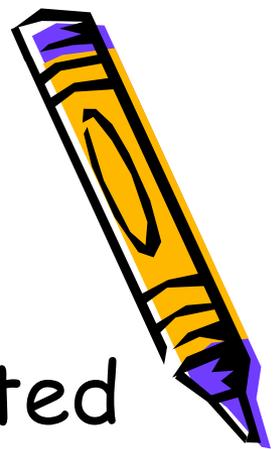
Special Populations: Children in Foster Care



- Over half experience developmental delays - this is four to five times the rate found in the general population
- Nearly 80 percent are “at risk” for a wide range of medical and developmental problems.
- More than 40 percent are born with low birthweight and/or premature, two factors which increase the likelihood of developmental delays.

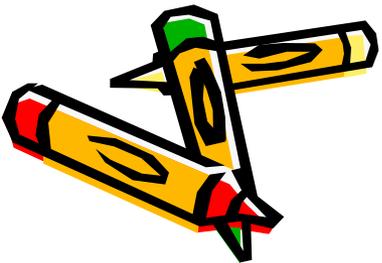


At-Risk: Abuse & Neglect

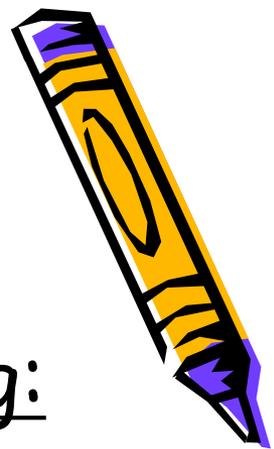


- Children who are abused or neglected experience far higher rates of physical, developmental, and emotional problems, including attachment disorders, social and emotional disturbances, cognitive deficits, neurobiological changes in the brain, and failure to thrive.....

(Jaudes & Shapiro, 1999)

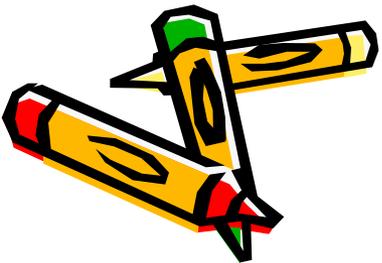


Most At-Risk: 0-3 Years



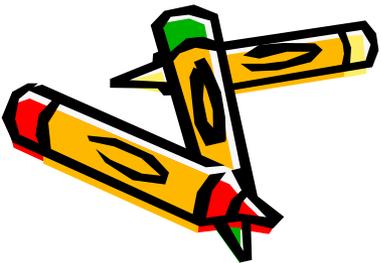
- Risk is greatest for the very young:
 - In 2005, children ages birth to 3 had the highest rates of victimization, at 16.5 per 1,000 children of same age.
 - More than three-quarters (76.6%) of the estimated 1,460 children who died as a result of child abuse or neglect that year were younger than 4 years.

U.S. Dept. of Health and Human Services, 2007



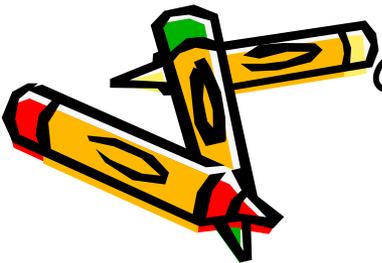
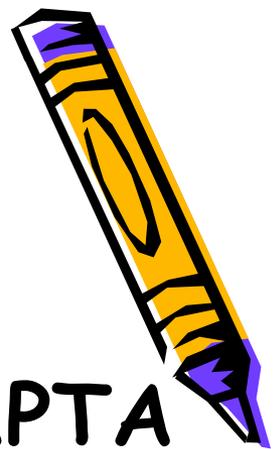
Our At-Risk Children

- Many young children under the age of 3 who experience abuse and neglect are placed in foster care:
 - One-quarter already have significant delays in motor development
 - One-half have significant delays in communication & cognitive development.
- (Jaudes & Shapiro, 1999; Spiker & Silver, 1999; U.S. GAO, 1995; Blatt, Saletsky, Meguid, 1997; Hochstadt, Jaudes, Zimo & Schachter, 1987).

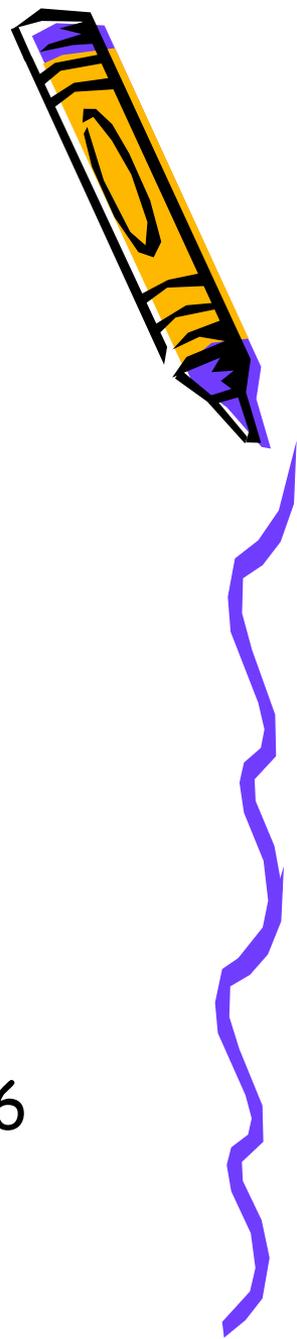


The Law: CAPTA

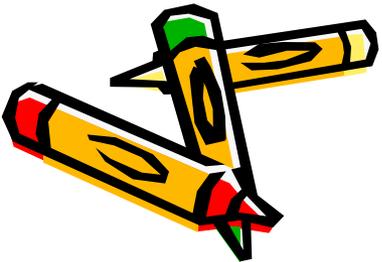
- In recognition of these risks, Congress's reauthorization of CAPTA (Keeping Children and Families Safe Act of 2003) required States to:
 - develop "provisions and procedures for referral of a child under age 3 who is involved in a substantiated case of child abuse or neglect to early intervention services funded under Part C of the (§ 106(b)(2)(A)(xxi))).
 - The 2004 reauthorization of the IDEA contains language parallel to CAPTA.



Federal & State Role



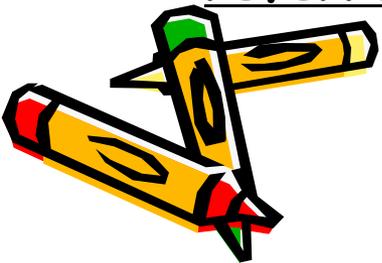
- Federal Law -
 - IDEA Part “C”: 20 U.S.C. § 1431
 - 34 C.F.R. Part 303
 - State Role: every state must
 - Establish its own definition of developmental delay
 - Establish criteria for eligibility for early intervention services
- Act 212: 11 P.S. § 875 / 55 Pa. Code Ch. 4226



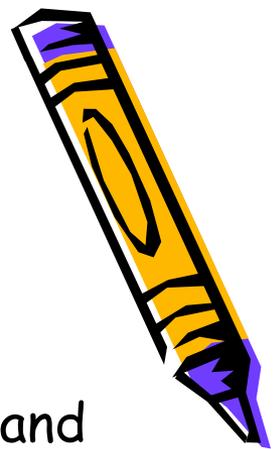
IDEA's Part C: Recent Changes To Ensure Services to Children in Care



- Congress added “infants and toddlers in foster care” to the Act’s “purpose clause” as children “historically underrepresented”
- State’s “lead agency” is directed to ensure that the state’s “child find system” targets infants and toddlers who are wards of the State and that this system is coordinated with the efforts of the “[c]hild protection and welfare programs responsible for administering CAPTA.
- Part C regulations now require that all infants and toddlers for whom abuse and neglect has been substantiated or who are identified as affected by illegal substance abuse or withdrawal symptoms resulting from prenatal drug exposure must be referred for to the Part C system for screening and/or evaluation



Changes To Ensure Services to Children in Care



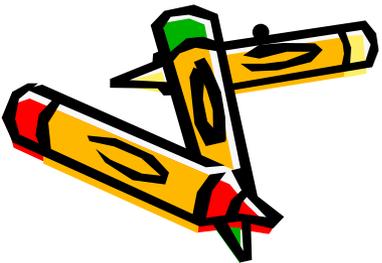
- **Primary referral sources** now include “Public agencies and staff to the child welfare system, including child protective service and foster care” are added as (that is entities who are directed to refer children who may be in need of early intervention services within 7 calendar days).
- **Definitions of “parent” and “ward of the State” and the rules for “surrogate parents”** were added or clarified and these now align closely with Part B.
- **At least one member of the State Interagency Coordinating Council must be from the state child welfare agency** responsible for foster care.



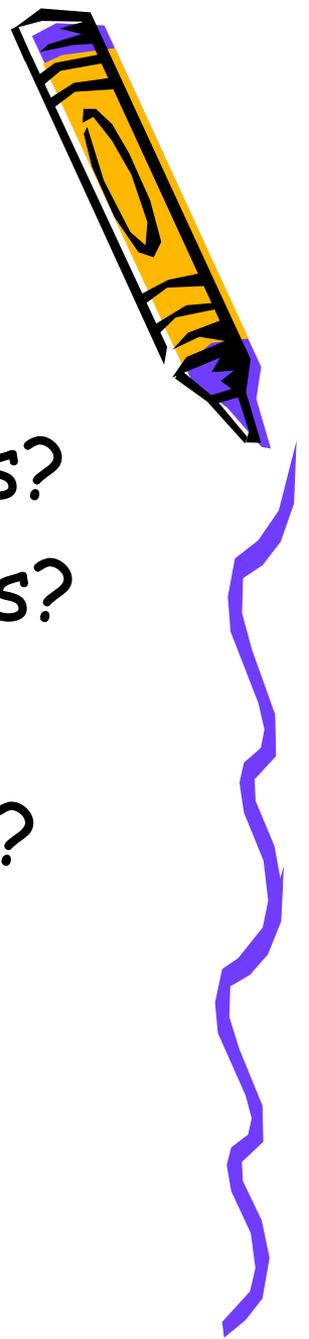
The Problem

- Despite the well documented need and eligibility, many children who have experienced abuse or neglect do not receive services.
- States nationwide report underidentification and underenrollment of children in child welfare in early intervention

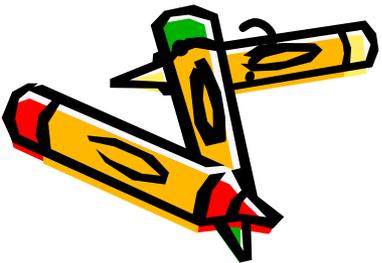
(Robinson & Rosenberg, 2004)



WHY?



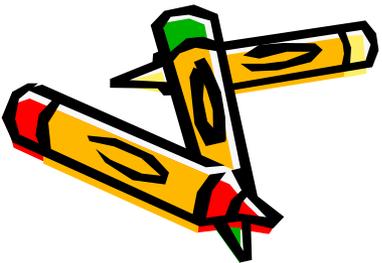
- Low referrals?
- Quality of assessments/screenings?
- Failure to obtain consent for MDEs?
- Failure to conduct MDEs?
- Failure to track children? Families?
- Lack of parent involvement?
- Failure to provide services?



Who Is Responsible?

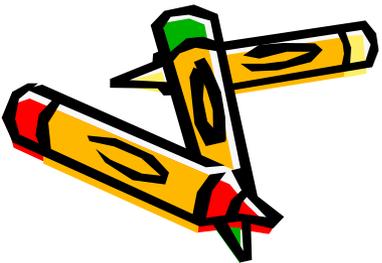
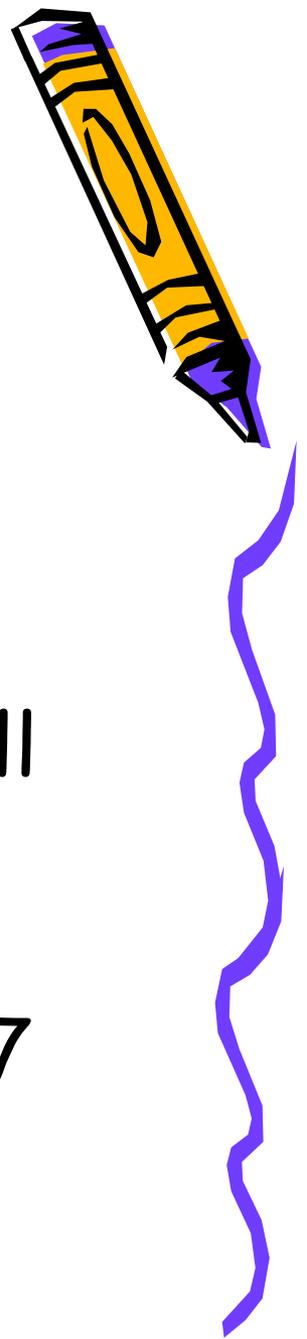


- Nebraska Protection and Safety refers a child under the age of three who is involved in a substantiated case of child abuse or neglect to the **Nebraska Early Development Network** for early intervention services funded under Part C of the IDEA (section 106(b)(2)(A)(xxi)).
- Agencies providing Part C services are required to provide comprehensive, coordinated, multidisciplinary, early intervention for infants and toddlers with disabilities or developmental delays and their families.



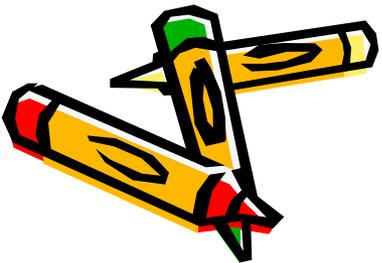
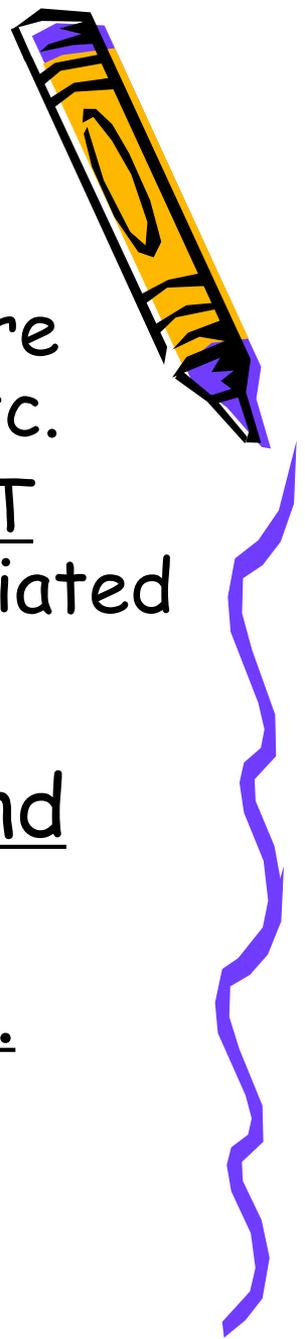
Who is Responsible?

- "The board of education of every school district shall provide or contract for special education programs and transportation for all resident children with disabilities who would benefit from such programs." Neb. Rev. Stat. 79-1127



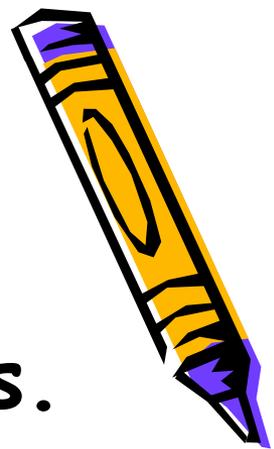
Step 1: Referral

- Who can refer?
 - Hospitals, doctors, parents, day care settings, social service agencies, etc.
 - Under CAPTA, Child Welfare MUST refer children who have a substantiated case of abuse or neglect.
- NOTE: The process does not and CANNOT end here.
- This is where the process begins.

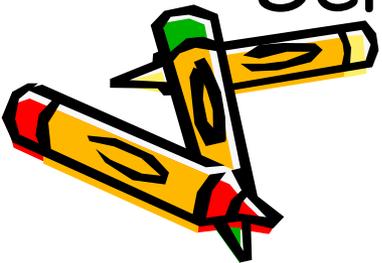


Step 1: Referrals

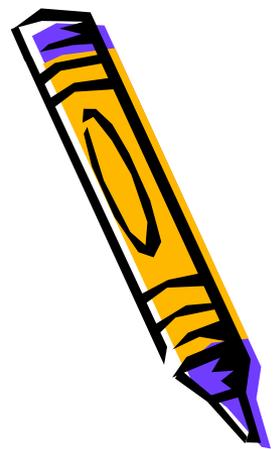
What's Working in NE



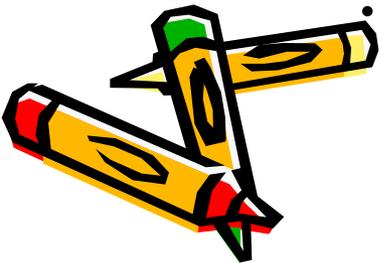
- Many states report low referrals.
- In 2011, Nebraska had a 100% CAPTA referral rate due to its automatic, electronic referral process.
- Implemented on January 1, 2011, the automated “CAPTA Referral System” between NDHHS Children and Family Services and Nebraska EDN works!



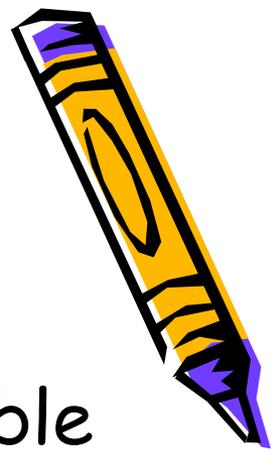
Step 1: Referrals cont' d...



- REFERRAL ≠ Permission to evaluate!
 - An agency **must** get permission from the child's "parent" to conduct an evaluation
 - Parent consent must be informed, voluntary, written
- Upon referral of child, the agency must:
 - Appoint a service coordinator ASAP
 - Within **45 days**, complete the multidisciplinary evaluation & develop
 - a service plan (IFSP) if child is eligible; **or**
 - Plan for further assessment and tracking if child is "at-risk" but not eligible for services



“Child Find” Duty

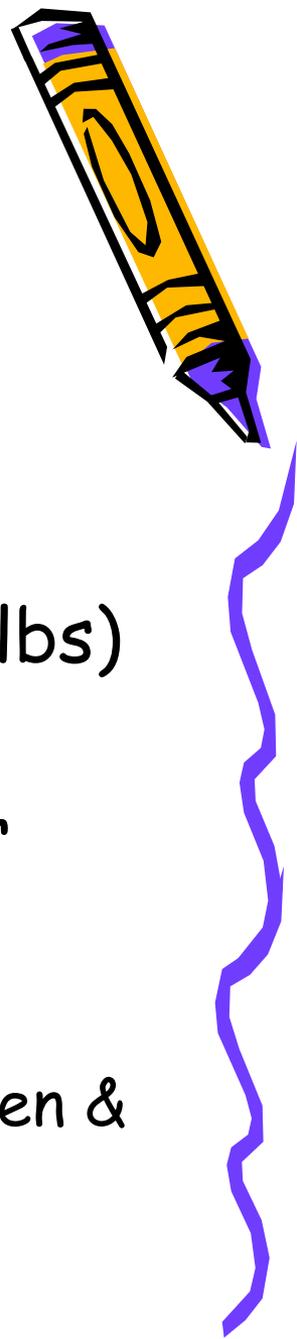


Agencies have a legal duty to locate eligible children, including:

- Children who are homeless &
- Children who are wards of the State
- Mandatory referrals for evaluation:
The State must have a system to refer child if:
 - Substantiated case of child abuse or neglect
 - Affected by illegal substance abuse or withdrawal due to prenatal drug exposure
 - Substantiated trauma from family violence.

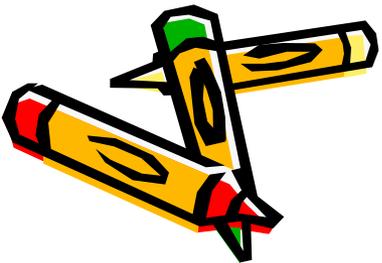


“Child Find”: State Law



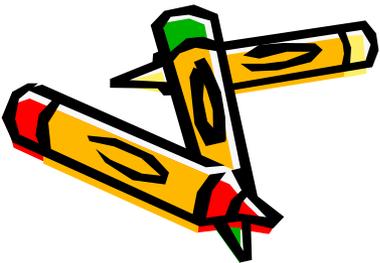
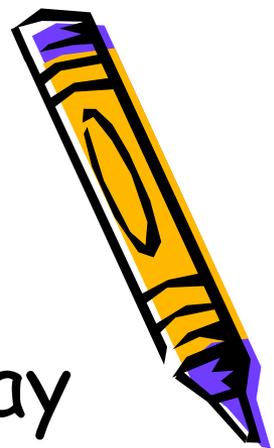
Some states add:

- Definition of “at risk”: (category of children who also should be tracked by DPW)
 - Birth weight under 1,500 grams (3.3 lbs)
 - Neonatal intensive care unit
 - Born to chemically dependent mother
 - And referred by doctor and parent
 - Seriously abused and neglected
 - As substantiated and referred by children & youth agency

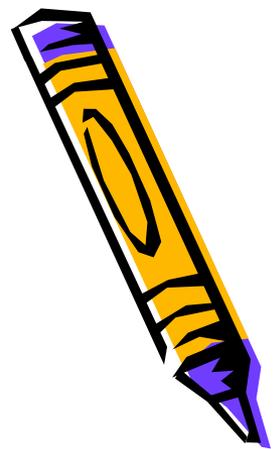


Who is Eligible?

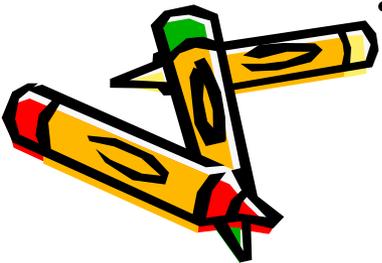
- Children age birth to 3rd birthday
- “Developmental Delay” in at least one of these areas of development:
 - Cognition
 - Communication
 - Social and emotional
 - Adaptive behavior
 - Physical (including vision and/or hearing)



Who is eligible? cont' d...

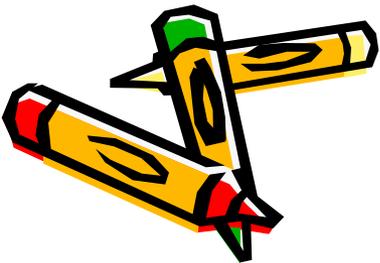


- Developmental delay defined:
 - *25% delay for child's age*
 - via appropriate diagnostic instruments/procedures
 - *Tests reveal 1.5 standard deviations below mean*
 - on accepted standard tests for infants/toddlers
- Diagnosed physical/mental condition that has a high probability of resulting in a delay
 - Ex: fetal alcohol syndrome, Down Syndrome, metabolic disorders, seizure disorders, etc.
 - *Informed clinical opinion*
 - especially if standardized tests are not available for child's chronological age or the developmental area



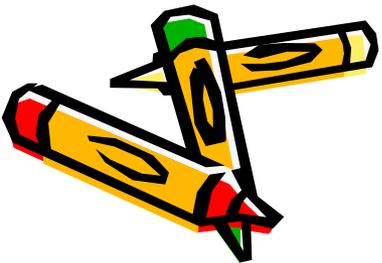
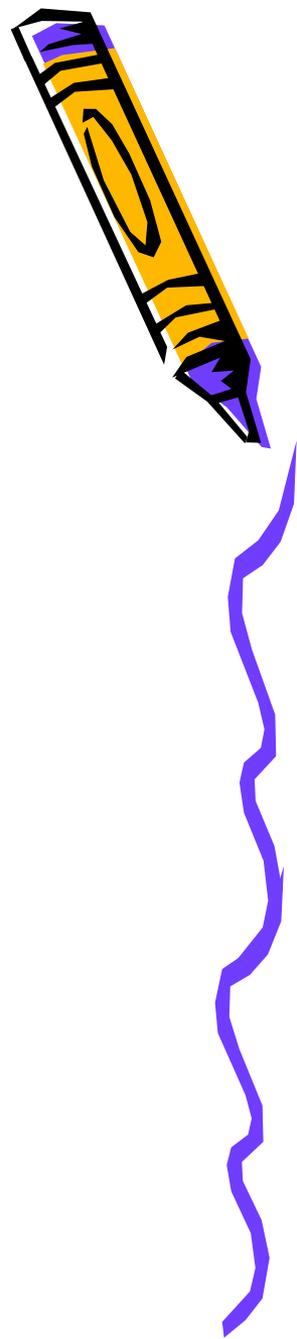
High Probability of Developmental Delay (Examples)

- Chromosomal abnormalities
- Genetic or congenital disorders
- Severe sensory impairments, including vision and hearing
- Inborn errors of metabolism
- Disorders reflecting disturbance of the development of the nervous system
- Congenital infections
- Disorders secondary to exposure to toxic substances, including fetal alcohol syndrome
- Severe attachment disorders

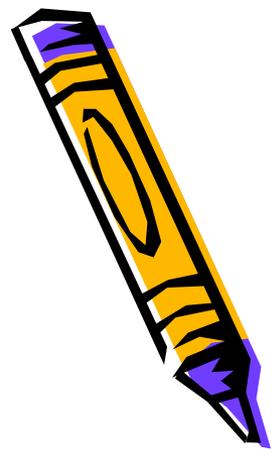


“Presumptive Eligibility”

- Down syndrome
- Fetal alcohol syndrome
- Hearing impairment
- Vision impairment
- Autism/PDD
- Spina bifida
- Cerebral palsy
- Trisomy 13, 18, etc
- Fragile X
- Hydrocephalus

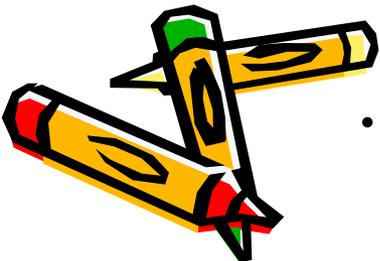


Step 2: Multi-Disciplinary Evaluation:

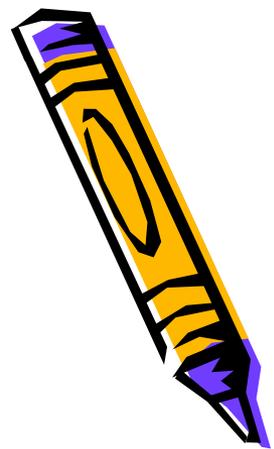


- Conduct of Evaluation:

- Initial eval. must be performed by someone not involved in providing services to the child
- Based on informed clinical opinion
- Conducted by persons trained in assessments
- Non-discriminatory, in parent's native language
- Must include
 - Review of relevant health status/history
 - Child's level of functioning and unique needs in each developmental area
 - Voluntary Family assessment (personal interview to determine resources, priorities, concerns of family)



Multi-Disciplinary Evaluation cont' d...



- Timelines
 - Must be done in time for an IFSP to be developed within **45 days** of referral
 - If cannot complete in time, EI agency must document why and create an “interim” IFSP (service plan)
 - Must conduct further MDEs at least **annually**
 - Written report to parents within **30 days**
- Note: may provide services while awaiting the evaluation

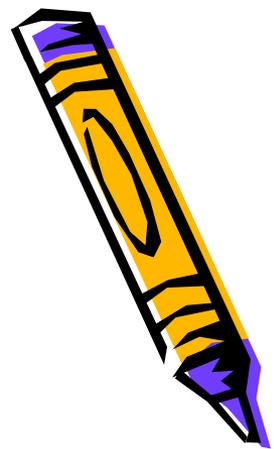


Use an “interim” IFSP

- Parent must consent



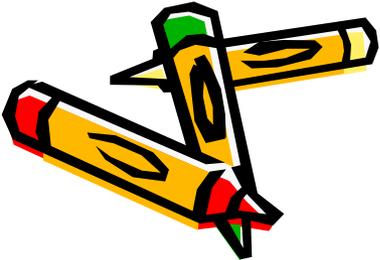
CAPTA & Multi-Disciplinary Evaluations in NE



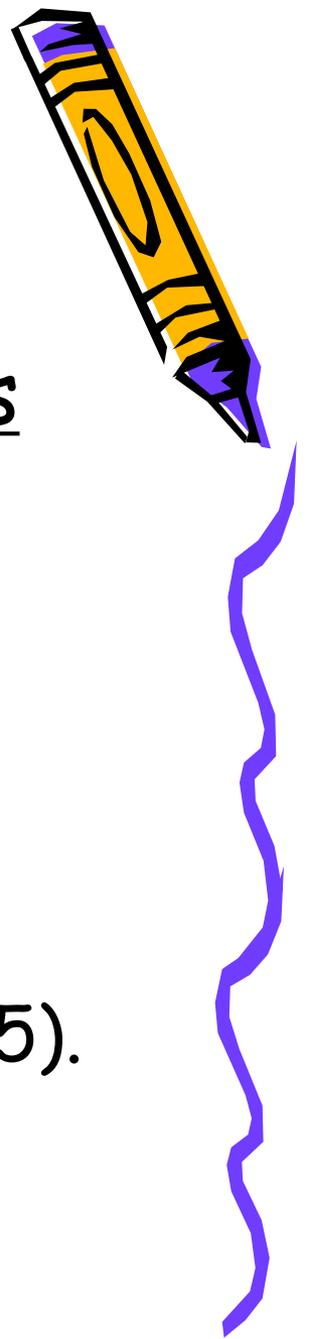
So, why did 68% of the 1,971 CAPTA referrals in Nebraska not receive a multidisciplinary evaluation?

- Only 10% (203) - Screened out after referral
- 35% (696) - Parent withdraw/refuse to participate in EDN intake/verification processes upon referral
- 21% (411) - Child/family unable to be located
- Only 1% (23) - Children/families moved out of state after referral and prior to verification occurring

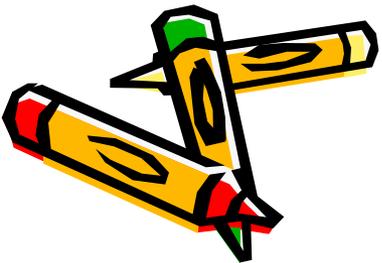
*Note: 157 children moved/transferred to another location in Nebraska after initial CAPTA referral; data was not available to determine outcome.



Major Barriers

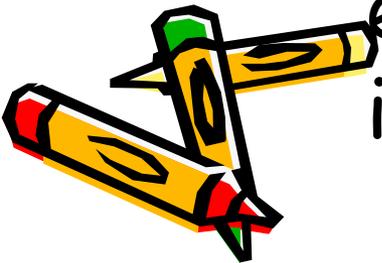
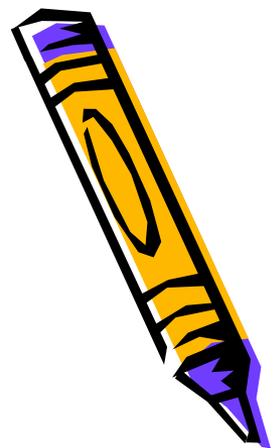


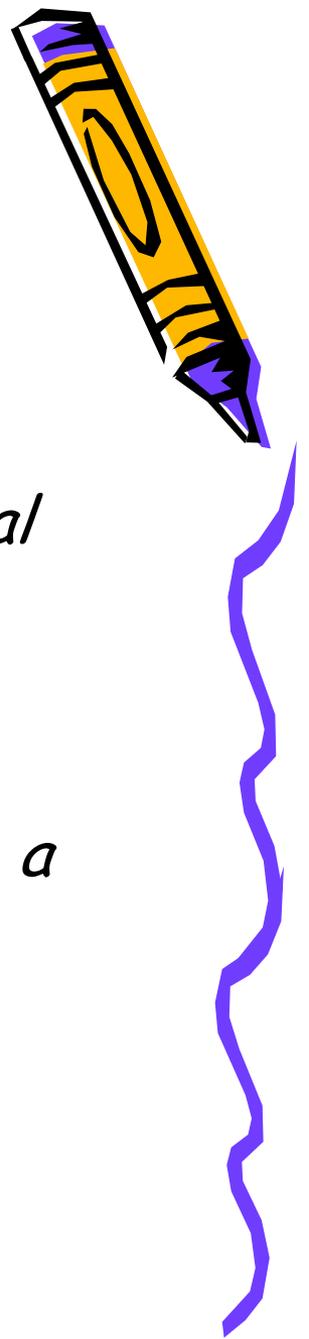
- Children often have more problems than are identified by referrals.
- Only one-third of EI problems are initially reported by caseworkers and/or foster parents.
 - (Halfon, Mendonca, & Berkowitz, 1995).



Other Major Barriers

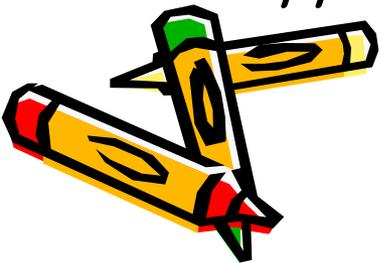
- Lack of consistent caregiver
- Lack of access to healthcare
- Parental consent and participation is required at each stage; parents are sometimes unknown or not found.
- Professionals are unfamiliar with child welfare policies and procedures, & strategies for engaging families “involuntarily involved” in a referral.



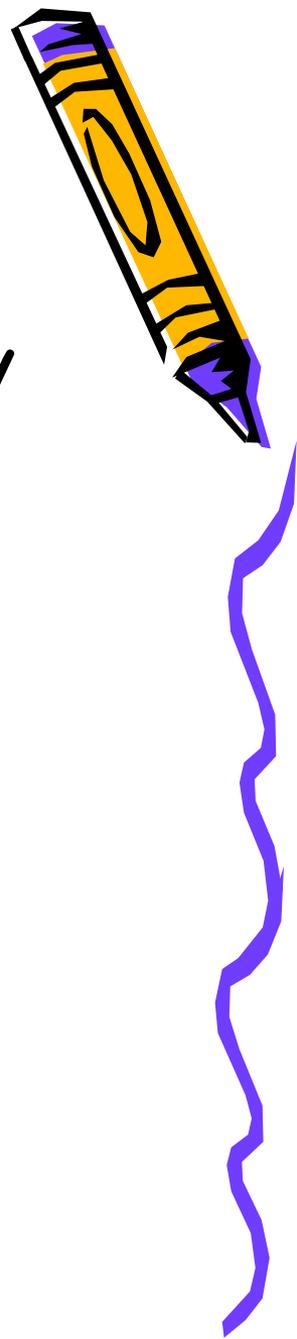


The Special Education Landscape

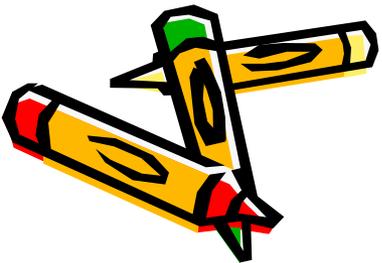
- **Special education is parent driven system**
Children in care may lack an active involved special education decisionmaker.
- **Child-find = knowledge**
Because children in care are highly mobile, their needs may remain unidentified and unknown to a “current” caretaker.
- **Time is of the essence**
*Appropriate services must be provided I
in a timely manner.*



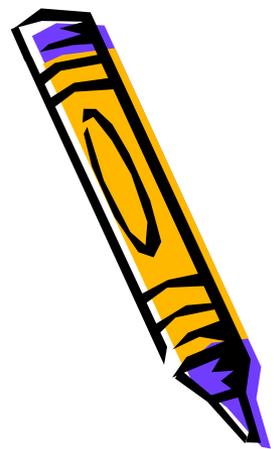
The Parent Landscape



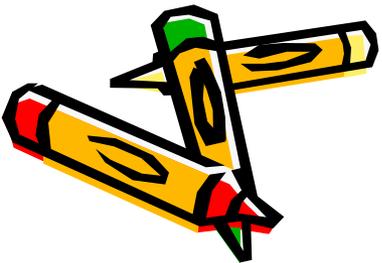
- Parents are part of an “involuntary process” when asked to consent.
- Parents may not understand the importance or EI, the process etc.
- Parents may be on the defensive.
- Communication is difficult.
- Parents **MUST** be involved in EI.



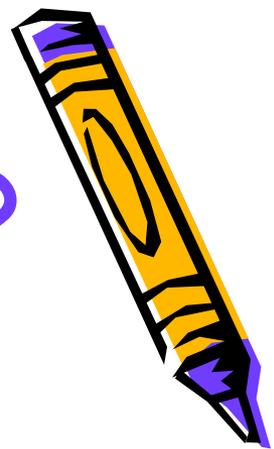
Child Welfare: The Linchpin



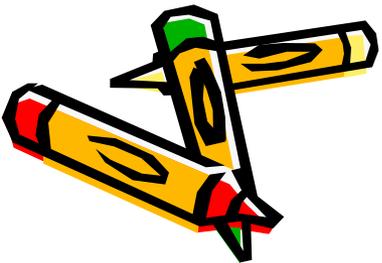
- Referral is NOT enough.
- Communicating & supporting parents is key. On-going communication req' d.
- Provide needed records & background for MDEs
- Ensure active involved decisionmaker
- **USE COURT TO APPOINT decisionmaker to consent.**



Who can provide consent?



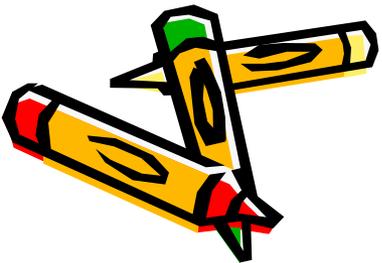
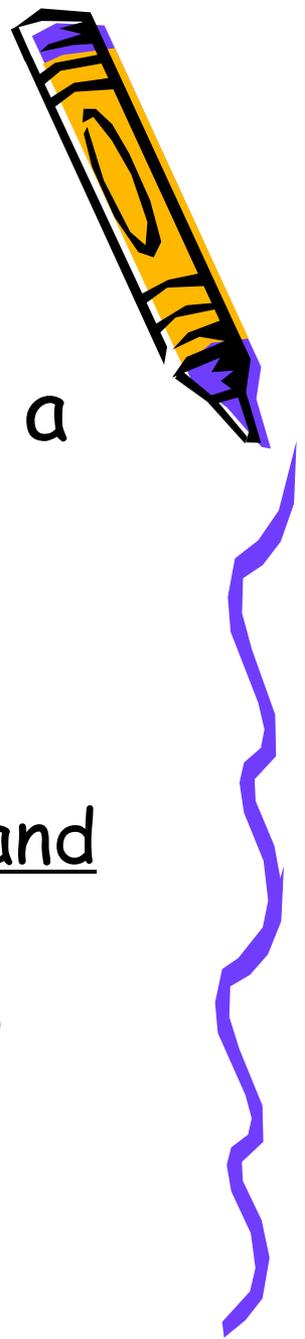
- “Parent” defined as:
 - Natural or adoptive parent
 - Guardian/legal custodian (but not the State)
 - Person acting in place of parent (such as grandparent/stepparent living with child)
 - Foster parent
 - Surrogate Parent



Surrogate Parent

Note: These are the rules for infants/toddlers, not older kids

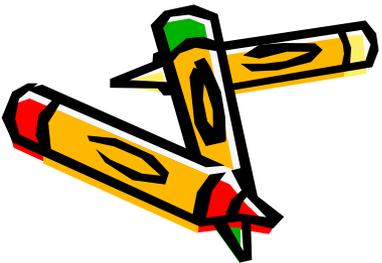
- When does an infant/toddler need a surrogate parent?
 - Parents can't be identified
 - Parents' whereabouts unknown OR
 - Child in custody of children & youth and
 - Parents can't be identified / found
 - Parents' rights have been terminated or
 - Parents are dead and there's no other parent



Parent Rights

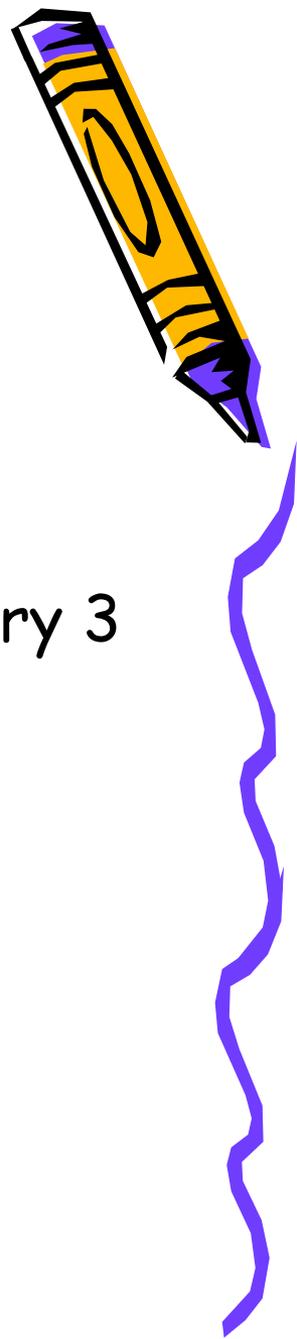


- Must receive written prior notice of:
 - Initiation or change to evaluations, services, placement; must be in parent's native language when feasible
- Right to consent (or refuse to consent) to:
 - Initial evaluation
 - Referral to "at-risk" tracking system
 - Initiating/changing any EI service(s) - the refusal to accept any one service can not jeopardize other services
- To request IFSP meeting at any time
 - To review child's EI records
 - To confidentiality of information



Step 3: Tracking

(if “at risk” but not eligible for EI)

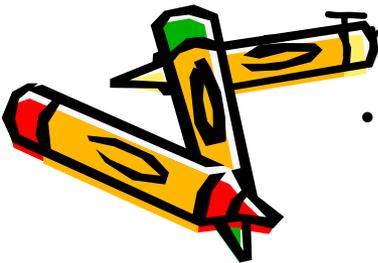


- Tracking Services:

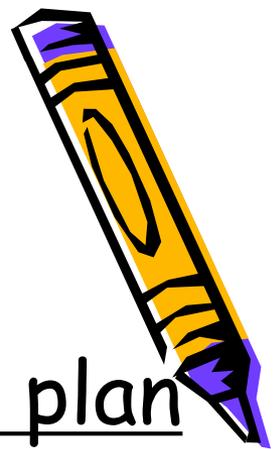
- The Agency must contact child’s family by phone, in writing, or in a meeting \geq once every 3 months
 - MDE may suggest more frequent contact
- Must use a standardized developmental checklist to review need for:
 - Further tracking
 - Further eval/re-eval for EI services eligibility

Tracking requires parental consent !

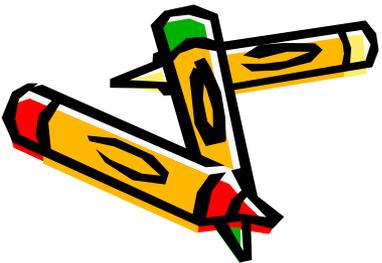
- Parent can request less frequent or NO contact



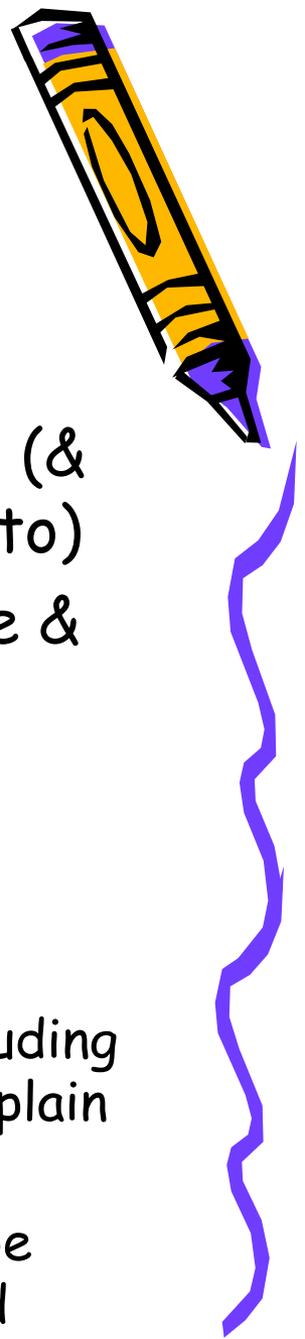
Step 4: IFSP (if eligible for EI)



- IFSP: individualized family service plan
 - Services must be free & based on the evaluation and assessment data
 - Written by a team of individuals:
 - Parent of infant/toddler (can invite others)
 - Service Coordinator
 - Person directly involved in the evaluation
 - Persons providing services to infant/toddler

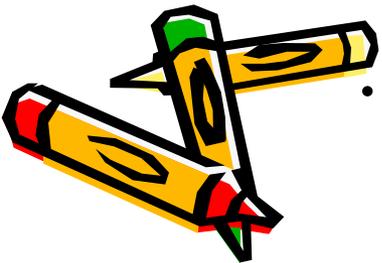


IFSP cont' d...

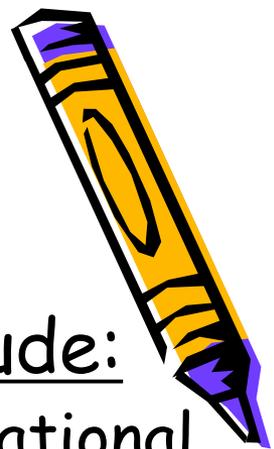


- What is included in the IFSP?

- Current levels in the 5 developmental areas (& results of family assessment, if consented to)
- List of Major outcomes child should achieve & how to measure child's progress
- Name of service coordinator
- Services child/family will receive
 - *How often*
 - *Where:* Should be in "natural environment" (including home, community settings); if not, IFSP must explain why not in natural setting
 - Whether service is *directly* to the child or will be *consultation* with someone working with the child



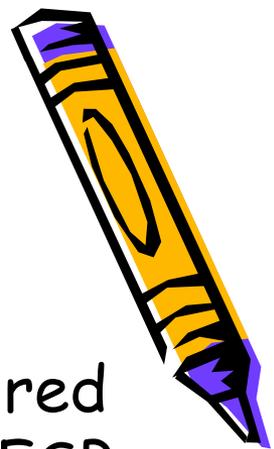
IFSP cont' d...



- Types of services (to child/family) include:
 - Special instruction, speech-language, occupational & physical therapies, audiology, nursing, nutrition, vision, assistive technology devices and services
 - Psychological services (including counseling)
 - Social work services (to help family help child)
 - Medical (for diagnosis & if necessary for child to benefit from another EI service)
 - **Service Coordination - (all receive this)**
 - Facilitate assessments, development and review of IFSPs, and transition to pre-school services
 - Coordinate/monitor delivery of EI services & more (even if services are not the responsibility of EI).



IFSP cont' d...

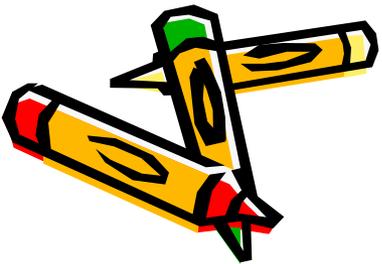
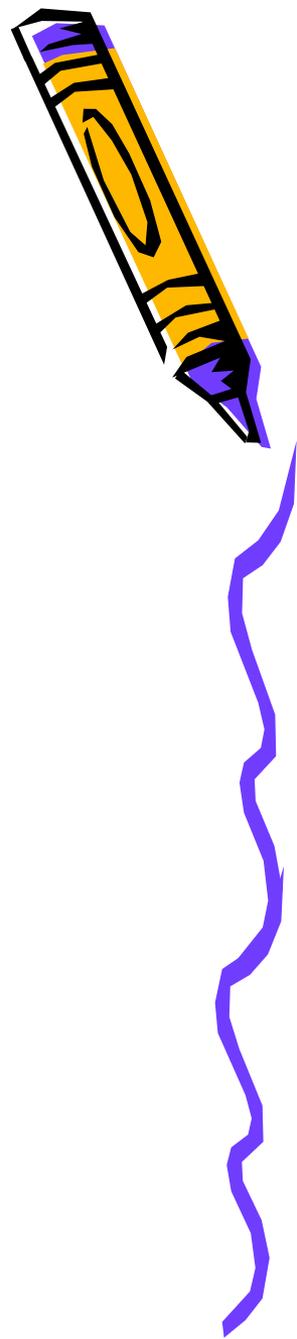


- Parent Consent to IFSP services:
 - Informed, voluntary, written consent required
 - Parent can refuse consent to part of the IFSP without jeopardizing rest of promised services
- Timelines:
 - Services must start within 14 days of IFSP
 - Can extend at parent's request, based on the child's needs, or at recommendation of the team including the parent.
 - Must review IFSP every 6 months
 - Is progress being made toward outcomes?
 - Should outcomes or services be changed?
 - Must meet to review/revise IFSP \geq annually (based on current evaluations)



Options for Resolving Disputes

- *Conflict Resolution* (voluntary)
- *Mediation* (voluntary)
- Dispute Resolution Process

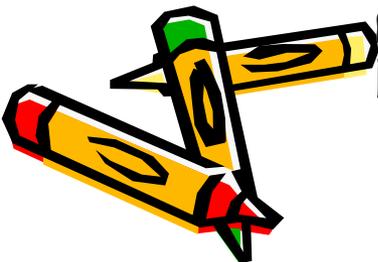


Options for Resolving Disputes

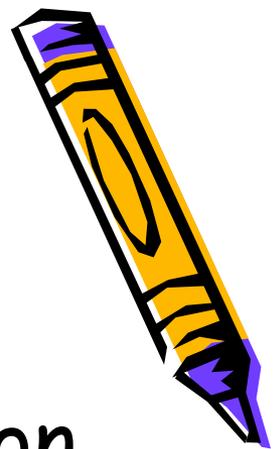
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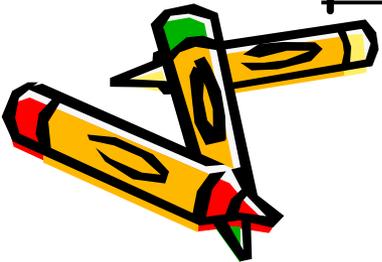
- *Complaint*
 - Legal violations (ex: timelines/IFSP not followed)
 - How: in writing
 - Short time frame to investigate/issue decision
- *Due process*
 - Disputes over eligibility, amount/type of services
 - How: letter to The Agency (or service coordinator)
 - Short time frame to hold hearing/issue decision
 - Parent may be offered conflict resolution and/or mediation but those are voluntary & can't delay hearing



Right to Services During Dispute



- During conflict resolution, mediation, and/or due process proceedings:
 - Child must continue to receive EI services currently being provided unless parent & The Agency agree to a change
 - If child is new to the system, during dispute child receives any services parent & The Agency can agree upon



EI Process Differs According to the Age of the Child



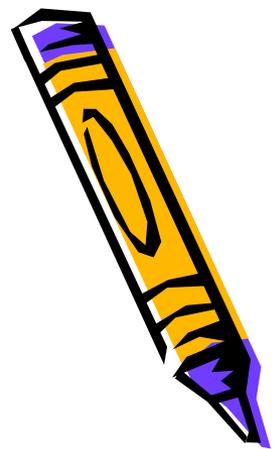
Early Intervention
IDEA

Birth to Age 3
Part C

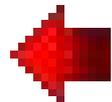
Age 3 to Age 5
Part B



Step 4: Transition to pre-school EI system

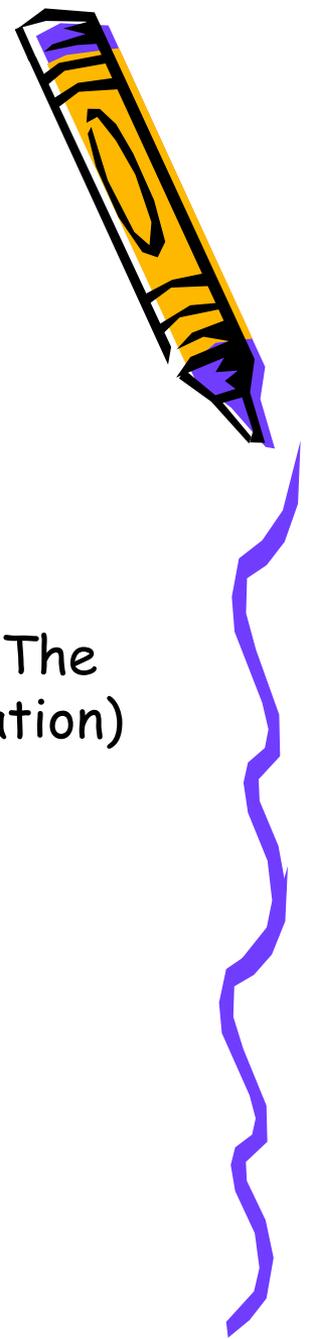


- Key differences in Pre-School EI:
 - Responsible Agency
 - Eligibility: from age 3 to “beginners”
 - Child must have a developmental delay or a qualifying disability (autism, MR, sensory impairment, emotional disturbance, etc.)
 - Note: delay must be shown, can't be based on informed clinical opinion or potential future delay
 - AND, as a result of the delay/disability, require specialized instruction

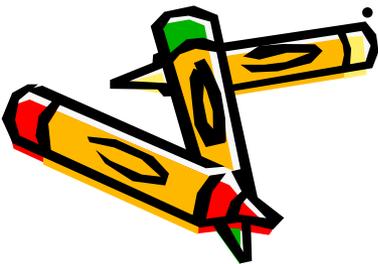


Step 4: Transition

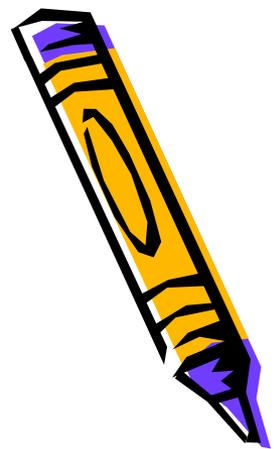
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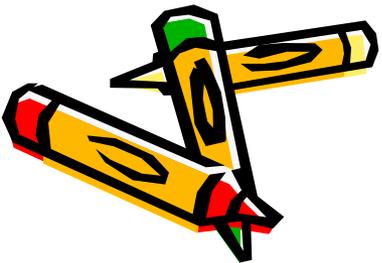
- Key differences in Pre-School EI:
 - Services
 - No nutrition counseling or service coordination
 - (But, may get service coordination if qualify for The Agency &/or Elwyn offers some service coordination)
 - Program:
 - Individualized Education Plan (IEP)
 - Placement:
 - Infant/Toddler EI: “natural environments”
 - Pre-school EI: “least restrictive environment”



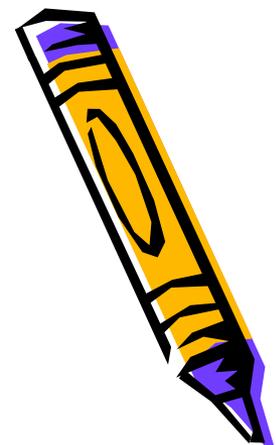
Step 4: Transition cont' d...



- Transition Process:
 - Before child turns 3, IFSP must address child's transition needs (services to prepare for change)
 - If parent consents, past IFSPs & evaluations are shared with preschool EI agency
 - At least 90 days before 3rd birthday:
 - (If family consents) The Agency, preschool EI agency and family meet to discuss the services child will receive upon turning 3 and to develop an IEP for the child.



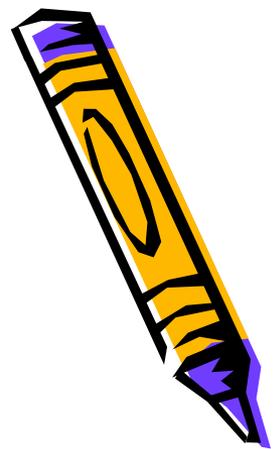
Step 4: Transition cont' d...



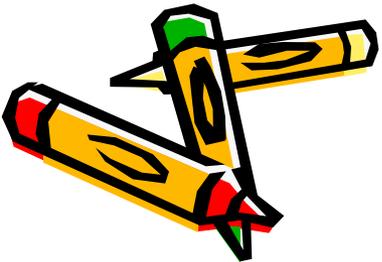
- Special Transition Process:
 - Children who are identified by The Agency within 60 days of their 3rd birthday are evaluated by the preschool EI agency
- Disputes re: proposed preschool IEP:
 - The child has a right to continue receiving the services in the last-agreed-to IFSP until the dispute is resolved through the hearing process
 - Although the same type and amount of services must be provided, the service provider may change (no right to the same staff)



Models and Best Practices



- Automatic CAPTA Referrals
- System for tracking children across multiple systems using “warehouse”
- Information/consent for parents
- System for promptly appointing parent when needed
- Quality & timing of MDEs



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