

**RESPONSE TO REQUEST
FOR INFORMATION**

RFI NO. 3062009

Submitted to

**Bureau of Early Intervention Services
Nevada State Health Division**

by:



THE FOUNDATION FOR POSITIVELY KIDS, INC.

in collaboration with,

**THE UNIVERSITY OF NEVADA
SCHOOL OF MEDICINE, LAS VEGAS
DEPARTMENT OF PEDIATRICS**

MARCH 25, 2009



March 25, 2007

Janelle Mulvenon
Bureau Chief
Bureau of Early Intervention Services
Nevada State Health Division

RE: Request for Information No. 3062009

Dear Ms. Mulvenon:

The Foundation for Positively Kids in collaboration with the Department of Pediatrics at the University of Nevada School of Medicine in Las Vegas, are pleased to submit this Response to the Request for Information provided by the Bureau of Early Intervention Services.

Over the past ten years, the Foundation for Positively Kids, Inc. (Positively Kids), based in Clark County, has become the premier provider of in-home skilled nursing care and supportive therapies for medically fragile children with severe disabilities, including children with developmental delays. Positively Kids' average daily census is 50 children or nearly 1,500 per month, giving us experience in delivering high volume services. Licensed nurses and therapists provide skilled care to children and families enrolled in Positively Kids' services. Programs include Respite Care, Home Health Care, Medical Daycare, Title IVB Medical Wrap Around Services for children in the Department of Family Services, ACT (Alternative Compatible Therapies), and a Family Court Advisory Program. Long range plans call for a 60-70 bed skilled pediatric nursing facility to be built on donated land in Henderson, Nevada over the next several years.

Positively Kids was founded by Fred Schultz, Chief Executive Officer. Mr. Schultz is a former home health administrator and licensed Respiratory Therapist. He has a degree in Respiratory Therapy from McComb College in Detroit, Michigan. Mr. Schultz was also credentialed as a Physician's Assistant through Wayne State College. Prior experience before coming to Nevada was in Florida where he administered a home health agency and a durable medical equipment program. He also managed a 24 skilled pediatric care facility connected with Broward General Hospital in Ft. Lauderdale, Florida. He has managed hospice programs in both Florida and in Las Vegas. An 11-member volunteer Board of Directors oversees programmatic and financial management. Serving as Medical Advisor is Dr. David Gremse, Chair of the Department of Pediatrics at the University of Nevada School of Medicine in Las Vegas.

During this ten year period, Positively Kids has had numerous encounters with neurologically impaired children and families in need of skilled and compassionate care, including those appropriate for early intervention services. Our programs devote considerable attention to

working with parents/caregivers to enable them to appropriately care for a child with disabilities or developmental delays giving us an understanding of the difficulties that families face in caring for a child with special health needs. Our services are provided in the home and in community settings. Examples include our Medical Daycare program that includes disabled children in child care settings with non-disabled children.

For the past several years, Positively Kids and the Department of Pediatrics at the University of Nevada School of Medicine in Las Vegas have collaborated on planning for and pursuing a number of health services for medically fragile children who are technology dependent, neurologically impaired, or who have disabilities and/or developmental delays. The Department has also provided pediatric subspecialists and pediatric residents who provide medical services through Nevada Early Intervention Services as a part of their medical training program. The Department has also provided Genetic Clinics which provide assessments for children with developmental delays.

Based on our experiences, we have outlined responses to the questions asked in the Request for Information that we believe would substantially improve the quality of diagnostic and intervention/support services provided to families in Nevada, would incorporate current, evidence-based, family-centered service models and intervention practices, would reduce the waiting time for families to receive services, and reduce costs for early intervention services.

Recently, inquiries about Positively Kids providing its program and services in northern Nevada/Washoe County have risen. Positively Kids is exploring the feasibility of developing respite and home health services for disabled and/or developmentally delayed children in the Reno/Carson area, working with local hospitals such as Renown Health that have expressed interested in providing a home for the program.

For each of the questions raised in the RFI, Positively Kids has provided a response and made recommended for possible solutions and/or actions to address issues raised. We would be pleased to discuss our response to the RFI and/or provide any other information you might need. Please feel free to contact me at (702) 262-0037 or at pos.kids@gmail.com.

Sincerely,

Fred Schultz

Fred Schultz,
Chief Executive Officer

David Gremse

David Gremse, MD
Chair, Department of Pediatrics

A. Description of Nevada's Early Intervention System

Question # 1. Describe your ideas on what and how Nevada's model for early intervention services should be delivered, using evidenced-based practices. Your model must ensure services are available and accessible statewide.

Considerable controversy has existed for some time as how to best organize Nevada's Early Intervention Services (NEIS) for developmentally delayed children. Due, in part, to rapid and sustained growth, coupled with chronic inadequate funding, and compounded by current state budget deficits and funding reductions, parents must wait longer than legislatively mandated for their child to receive care. Lack of resources has also resulted in some children receiving less intensive services or fewer hours of therapy than is recommended. Some families never receive recommended services. Calls for privatization have been met with dismay by some parents who have had successful experiences with NEIS while other families are extremely frustrated by the lack of attention their child has received.

In earlier times when primarily rural or sparsely populated states, often Western states, were developing systems of care, there were few local community agencies that could effectively meet the needs of developmentally delayed children. Consequently, state agencies developed these systems and employed workers that were hired as state employees. In assessing the needs of Nevada's system of care for developmentally delayed children and researching systems in use in other states, it is suggested that with some operational changes to develop a more uniform, coordinated system of care, the state's Bureau of Early Intervention Services along with a set of qualified community-based agencies contracted to provide services, could create a system that works to the benefit of Nevada's developmentally delayed children and their families.

Today in Nevada both state agencies and contracted community provider agencies can contribute to a system of care that is of high quality and that meets the needs of local children and their families. Agencies like Positively Kids have emerged with extensive experience in working with children and family, both disabled and developmentally delayed.

Current research and practice identify at least eight models of "evidence-based" early intervention service delivery (*Pletcher, Younggren, Romanick, and Johnson, 2008*). The first two models include:

- Multidisciplinary
- Interdisciplinary

Generally speaking, a multidisciplinary approach brings to bear multiple disciplines in deciding on delivering care and treatment for a developmentally delayed child. Multiple professionals work together on a team with the family to develop the individualized family service plan (IFSP) and provide early intervention services in either a clinic setting and/or the natural environment. The team is responsible for selecting the most appropriate service delivery model based on the specific needs of the child and family. However, in some multidisciplinary approaches, disciplines may not talk with one another as much as needed and care may not be less than coordinated.

In the Interdisciplinary Model which is used by Positively Kids in providing services for medically fragile/severely disabled children, not only are multiple disciplines involved, they

form an “interdisciplinary team” and collectively share decision making on meeting the needs of the child. Of utmost importance is incorporating **parents/caregivers as an integral part of the Interdisciplinary Team**, ensuring that recommended approaches and strategies can be appropriately carried out in each family situation.

Six other, approaches to care for developmentally delayed children include the following models. Definitions and citations for these models are found in Exhibit A on Page 11.

- Trans-disciplinary
- Primary Service Provider
- Coaching
- Consultation Services
- Collaborative Team Model
- Trans-agency

Perhaps more important than choosing one model is to understand that each family needing early intervention services is unique. Approaches to working with each child and family need to draw upon the resources of appropriate models, but must be tailored to the individual child and family situation and circumstances. An Interdisciplinary Team approach, borrowing from the Collaborative Team model - (Team members work in partnership and pool resources; all team members are involved in planning and monitoring goals and procedures, although each team member’s responsibility for the implementation of procedures may vary; Team members jointly share ownership and responsibility for intervention objectives), - allows early intervention team members to apply appropriate strategies and interventions from the full array of evidence-based models depending on the unique needs of each individual family. The goal of this model is to provide comprehensive, coordinated, family-centered care.

2. *Describe your ideas regarding the balance of services provided in the natural environment and/or clinic model. How would you most efficiently and effectively provide services to as many children as possible while demonstrating compliance with the Part C requirement for natural environment recognizing the limited pool of licensed therapists?*

The Part C, IDEA requires that “To the maximum extent appropriate, early intervention services are to be provided in natural environments, including the home and community settings in which children without disabilities participate. Natural environments are defined as “A natural environment means settings that are natural or normal for the child’s age peers who have no disabilities.” Positively Kids has been providing services for children in the home for the past ten years and has experience in providing services in community settings that include children without disabilities. In 2005 we began a Medical Daycare program that puts children in standard community daycare programs with medical support staff that accompany the child. Today that program is coordinating services with local Head Start Programs throughout Clark County.

As the fundamental premise for serving developmentally delayed children is to provide family centered care that meets each child’s and family’s individual needs, balancing requirements for clinical vs natural environments needs to be based on individual need.

3. Describe your model including all components such as: intake process for each region of the state (rural, northern and southern), the evaluation process, the development of the Individualized Family Service Plan (IFSP), the delivery of services for IFSP's, and transitioning process when the child reaches his/her third birthday or attains age appropriate developmental skills.

Several suggestions regarding the process whereby children and families complete the intake assessment and learning interventions/support services are recommended are made below:

a. Use of a tiered system of assessment and referral for interventions/care – to maximize limited resources, children and families seeking early intervention services could be assessed on a three tiered system. Children/families in Tier I would need the lowest level of intervention/support, assuming no medical complications. An example might be a 24 month old child who is unable to meet the vocabulary standards for his/her age and could increase vocabulary with drills provided by the family. NEIS speech therapy staff would teach the family how to do the drills and would monitor the child for progress. Children in Tier II will need greater intervention/support in the case where a physical disability is affecting speech and language. Children in Tier III have an unquestionable need for support and intervention. As an example, a child with a tracheostomy or chronic respiratory problem resulting from extreme prematurity may have a compromised airway that is impairing their ability to form words. NEIS staff would work with the family to restore care for the tracheostomy and to help restore or develop speech. Staffing skills and costs of services are tiered to help manage patient flow and service delivery.

b. Use of a team approach to care, but one that is truly interdisciplinary where, based on the child and family assessment, the team only uses service providers appropriate to meet the needs of that child/family. Teams have a Support Services Coordinator who serves as the lead team member, who coordinates necessary team members and services for each family, and who serves as the point of contact for that family. We would continue to incorporate the Department of Pediatrics medical resident rotations and special clinics to provide full and comprehensive services.

c. Referrals for children who are in a local hospital receive an immediate Preliminary Intake and Assessment (within 7 business days from the initial contact) either at the hospital BEFORE discharge, to determine what, if any services may be needed.

d. Rather than in the home or other community setting, we recommend the use of an Assessment Center that could provide a setting that enables families to be comfortable while their children wait to be seen. and where expert staff is available should an emergency occur such as a sudden seizure. The Assessment Center would also foster the opportunity for parents to connect with each other to develop support systems for them and their children in the program. Children with severe delays and/or birth defects need to receive a genetic assessment to determine the cause of the delay and guide treatment decision-making.

e. Based on this initial assessment the Support Service Coordinator assembles the appropriate service team members including the family. Together it is determined if the child needs any further evaluation and/or the team begins to develop a IFSP including a focus on planning for transitioning out of care at the beginning of the planning process.

f. For children who are family/parent/physician referred, within 7 days of the contact, an NEIS Support Services Coordinator goes to the home and does an Preliminary Intake and Assessment; following this initial assessment the Support Services Coordinator will identify team member disciplines that need to be a part of developing the IFSP; The team including the family will determine appropriate support services and where those services are best provided for each individual family.

g. Each IFSP contains objectives, intended outcomes and length of stay recommendations.

h. Planning for discharge from NEIS begins immediately so that family members understand the importance of their being the primary provider of services for their child. Once the objectives of the IFSP are met the child can be released from NEIS. However, it is important that families know that children can continue to receive community services (respite, daycare, parent support groups, etc..) through private contracted providers, largely non-profit, that can bring other sources of revenue (grants, foundations, etc.) to bear.

i. Two other critical issues for discussion include Reimbursement for services and the need for a strong Parent Teaching and Support Program.

- *Reimbursement* – We recommend that the reimbursement schedule be based on the Tier System that determines the degree of severity of need for each child/family. Payment for services is gradually increased as the higher tiers of service are determined. In general it is always more cost effective to “bundle” services, allowing for “outliers” or exceptions to the basic services. Positively Kids would support the development of uniform billing standards to be used across the state.
- *Parent Teaching and Support Program* - Given that families are central to the support services provided to their child and given the extreme emotional stress and strain that often occurs when families have a severely delayed or disabled child, for example an autistic child, we believe it is essential that families have access to a strong Parent Teaching and Support Program. Yes, teaching occurs in the natural environments, but parents also need a place where they can learn about their child’s condition or find out about long term financial resources that may be available to them or simple have a chance to talk to other parents who are facing similar situations and share resources and ideas. The use of Parent Advocates is recommended to provide a resource for parents through access to other parents or family members who have experienced caring for a special needs child.

4. *In your description, if the activity of a single point of entry (SPOE) is included, please add detail on the functions of a SPOE.*

Benefits of a single point of entry include the ability to have client records consolidated, to maintain coordinated data collection and reporting, to streamline documentation to ensure Part C requirements are met, and the ability to centralize contracted therapists and other service providers that need to be involved in providing support for families with developmentally delayed children.

5. *Who should deliver the services and specify the level of responsibility? A few examples include but are not limited to: state-operated programs only, combination of public and private agencies/providers, private agencies only, regional consortiums or networks, a hybrid, etc.*

In considering whether, or how, to reorganize early intervention services, it is useful to examine the roles and attributes that both state agencies and contracted provider agencies skilled in working with children, can bring to the system. Positively Kids contends that a working with the state as a public agency in an overall planning and service delivery management role, in combination with qualified private, non-profit providers offers some clear benefits to having only state run or only contracted services. In this combination form with both the state agency and contracted providers, the role of each player is key and is outlined below.

State Agency roles revolve around:

- Setting programmatic operating standards in compliance with Part C, IDEA regulations
- Providing training/technical assistance to ensure quality services,
- Allocating resources in order to balance funding for diagnostic and treatment services
- Monitoring and evaluating programs and services to ensure continuity of care and quality services.

Contracted, non-profit provider agency roles revolve around:

- Providing local, affordable and accessible community-based services,
- Ensuring services for families from diverse racial/ethnic, cultural and socio-economic backgrounds that are dynamic and individualized to reflect the child's and family members' preferences, learning styles and cultural beliefs
- Enhancing the capacity of Nevada families to meet the developmental and health-related needs of children birth to age three who have delays or disabilities by providing quality services and support to families and their children.

With strong state leadership in standard setting, training, and accountability for funds and services, community providers have a conceptual framework within which to provide individualized local services. Contracted community agencies often have more flexibility in areas of operation that can be difficult at the state level. Key examples include hiring and firing workers, setting salaries and benefits for workers, integrating cultural considerations at every level of care, contracting for services, and others.

6. *If the state were to transition to your envisioned model, describe your recommendations for how this transition could occur.*

In envisioning the organizational structure described above, NEIS day-to-day service operations would be contracted to non-profit community based organizations such as or similar Positively Kids. State employees currently working at NEIS facilities would become employees of Positively Kids. These employees would be brought into the agency at their salaries and would receive a fringe benefits package to include retirement, health insurance, etc. Staffing would include a combination of full and part-time staff, but planning would be done to achieve one or two full time therapists (OT, PT, Speech, Developmental Specialists, etc) rather than a collection of part-time persons that may be less likely to have the commitment to services that a full time position would afford. Positively Kids also uses a Quality Improvement/Quality

Assurance Committee to ensure that services are timely, are multi-disciplinary and monitor achievement of outcomes. This same approach would be applied to NEIS services.

Service delivery would transition to a more pro-active model of reaching out to families to begin assessment and IFSP planning as early as possible. Through relationships that Positively Kids has with the Occupational Therapy program at Touro University, we have access to OT specialists and to senior students who, with supervision, can provide services. We currently employ contracted speech and physical therapists who, among others in the community, would be considered for full time employment.

Transition to a private, non-profit corporation should not create any major disruptions to services. Positively Kids would partner with Area Health Education Center of Southern Nevada to develop and deliver an ongoing in-service training program to keep NEIS staff fully abreast of change in the field of services for developmentally delayed and/or severely disabled children.

7. What are key questions that the state should consider before choosing a particular approach to a service delivery system?

Key questions might include:

What private providers are or could become eligible to provide early intervention services?

What training or technical assistance is available to support community-based providers in delivering early intervention services?

What can be done to provide genetic clinic services to EIS children?

How can community-based EIS services better integrate and foster coordinated care with local pediatricians in the community?

What agencies can provide social support services to supplement early intervention services when needed?

8. Describe how you would sustain this change and make it statewide.

New service delivery and contracting models could be implemented on a trial or pilot basis in Clark County and could later be transitioned to other regions of the state. Assuming that the proposed combination of state agency and contracted providers was effective in reducing the time that families wait for services and was providing high quality support for families caring for a developmentally delayed child, the model could be further implemented in other regions of the state.

In general, Positively Kids recommendations made herein have similar desired outcomes and are consistent with recommendations from the various workgroups that have convened across the state. Specifically,

- Partnering with community providers throughout the state by building partnerships in the Northern region and expanding our existing partnerships in the South.

- Working collaboratively at modifying the intake and evaluation processes to make it as streamlined and efficient as possible therefore using our resources to the best of our abilities.
- Developing new procedures to ensure children with possible Autism receive early screening and diagnosis.
- Balancing workflow between natural environment and a more traditional medical model of a clinic setting.
- Establishing consistent billing procedures with the use of an electronic scheduling and billing system statewide.
(BA 3208 Early Intervention Services for Children under the Age of Three with Disabilities.)

In responding to the RFI, Positively Kids and the Department of Pediatrics have attempted to share our concerns for quality care for our developmentally delayed and/or disabled children and to offer suggestions to streamline and upgrade service delivery. We would be pleased to answer questions or to provide any other information that would be helpful.

Exhibit A

Models of Service Delivery for Developmentally Delayed Children and their Families

- *Trans-disciplinary* - Professionals share roles & see the child as a whole in the context of the family.
- *Primary Service Provider (PSP)* - Linked to a Trans-disciplinary model. PSP works in close collaboration with other team members integrating & synthesizing information shared to deliver efficient & comprehensive support. Service delivery by one person with supporting services provided through joint visits & consultation. The designation of the PSP should be a team decision and individualized for each child and family. It is a viable model if it includes careful consideration of which team member offers the best match of expertise and relationship with the family, and is not based only on logistics, such as availability or cost. When using the PSP model, the team must communicate regularly to support one another—as well as the child and family—to ensure maximum progress.
- *Primary Coach* - Coaching – “...an interactive process of observation and reflection in which the coach promotes a parent’s or other care provider’s ability to support a child’s participation in everyday experiences and interactions with family members and peers across settings”

Primary Coach Approach to teaming -“...assigns one member of a team as the primary coach, where he or she receives coaching from other team members, and uses coaching with parents and other primary caregivers to support and strengthen their confidence and competence in promoting child learning and development.”

- *Consultation Services*- Not tied to one particular model, but flexible to meet the individual needs of children and families and variation in program structure.
- *Collaborative Team Model* - In this model:
Team members work in partnership and pool resources.
All team members are involved in planning and monitoring goals and procedures, although each team member’s responsibility for the implementation of procedures may vary.
Team members jointly share ownership & responsibility for intervention objectives.
- *Trans-agency* - Provides a process for the primary service provider, the family, and staff from outside agencies serving the family, to come together to develop an across agency service plan for the child and the family