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FOR CONSIDERATION By the Committee on Children, Families, and Elder Affairs

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A bill to be entitled An act relating to prenatal services and early childhood development; amending s. 383.141, F.S.; revising the requirements for the Department of Health to maintain a clearinghouse of information for parents and health care providers on developmental evaluation and early intervention programs; requiring the clearinghouse to use a specified term; revising the information to be included in the clearinghouse; amending s. 391.025, F.S.; revising the components of the Children's Medical Services program; amending s. 391.026, F.S.; requiring the department to serve as the lead agency to administer the Early Steps Program; amending s. 391.301, F.S.; deleting a provision relating to legislative findings and establishing the Early Steps Program within the department; providing requirements and responsibilities for the program; amending s. 391.302, F.S.; defining terms; revising the definitions of certain terms; amending s. 391.308, F.S.; renaming the "Infants and Toddlers Early Intervention Program" as the "Early Steps Program"; requiring, rather than authorizing, the department to implement and administer the program; providing performance standards; revising the duties of the department; establishing eligibility criteria for the program; providing duties for local program offices; requiring the development of an individual family support plan for each child served in the program; requiring referral for services by a local program

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office under certain circumstances; requiring the local program office to negotiate and maintain agreements with specified providers and managed care plans; requiring the local program office to coordinate with managed care plans; requiring the department to submit an annual report to the Governor, the Legislature, and the Florida Interagency Coordinating Council for Infants and Toddlers; designating the Florida Interagency Coordinating Council for Infants and Toddlers as the state interagency coordinating council required by federal rule; providing requirements for the local program office and local school district to prepare children for the transition to school; amending s. 413.092, F.S.; conforming provisions to changes made by the act; amending s. 1003.575, F.S.; conforming provisions to changes made by the act; repealing ss. 391.303, 391.304, 391.305, 391.306, and 391.307, F.S., relating to requirements for the Children's Medical Services program, program coordination, program standards, program funding and contracts, and program review, respectively; providing an effective date.

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Be It Enacted by the Legislature of the State of Florida:

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Section 1. Subsections (2) and (3) of section 383.141, Florida Statutes, are amended to read:

383.141 Prenatally diagnosed conditions; patient to be provided information; definitions; information clearinghouse;

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advisory council.-

- (2) When a developmental disability is diagnosed based on the results of a prenatal test, the health care provider who ordered the prenatal test, or his or her designee, shall provide the patient with current information about the nature of the developmental disability, the accuracy of the prenatal test, and resources for obtaining relevant support services, including hotlines, resource centers, and information clearinghouses related to Down syndrome or other prenatally diagnosed developmental disabilities; support programs for parents and families; and developmental evaluation and intervention services under this part s. 391.303.
- (3) The Department of Health shall develop and implement a comprehensive information clearinghouse to educate health care providers, inform parents, and increase public awareness regarding brain development, developmental disabilities and delays, and all services, resources, and interventions available to mitigate the effects of impaired development among children. The clearinghouse must use the term "unique abilities" as much as possible when identifying infants or children with developmental disabilities and delays. The clearinghouse must provide:
- (a) Health information on conditions that may lead to impaired development of physical, learning, language, or behavioral skills.
- (b) Education and information to support parents whose unborn children have been prenatally diagnosed with developmental disabilities or whose children have diagnosed or suspected developmental delays.

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(c) Education and training for health care providers to recognize and respond appropriately to developmental disabilities, delays, and conditions related to disabilities or delays. Specific information approved by the advisory council shall be made available to health care providers for use in counseling parents whose unborn children have been prenatally diagnosed with developmental disabilities or whose children have diagnosed or suspected developmental delays.

- (d) Promotion of public awareness of availability of supportive services, such as resource centers, educational programs, other support programs for parents and families, and developmental evaluation and intervention services.
- (e) Hotlines specific to Down syndrome and other prenatally diagnosed developmental disabilities. The hotlines and the department's clearinghouse must provide information to parents and families or other caregivers regarding the Early Steps Program under s. 391.301 and any other developmental evaluation and intervention program. Information offered must include directions on how to obtain early intervention, rehabilitative, and habilitative services and devices establish on its Internet website a clearinghouse of information related to developmental disabilities concerning providers of supportive services, information hotlines specific to Down syndrome and other prenatally diagnosed developmental disabilities, resource centers, educational programs, other support programs for parents and families, and developmental evaluation and intervention services under s. 391.303. Such information shall be made available to health care providers for use in counseling pregnant women whose unborn children have been prenatally

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diagnosed with developmental disabilities.

- (4) (a) There is established an advisory council within the Department of Health which consists of health care providers and caregivers who perform health care services for persons who have developmental disabilities, including Down syndrome and autism. This group shall consist of nine members as follows:
  - 1. Three members appointed by the Governor;
- 2. Three members appointed by the President of the Senate; and
- 3. Three members appointed by the Speaker of the House of Representatives.
- (b) The advisory council shall provide technical assistance to the Department of Health in the establishment of the information clearinghouse and give the department the benefit of the council members' knowledge and experience relating to the needs of patients and families of patients with developmental disabilities and available support services.
- (c) Members of the council shall elect a chairperson and a vice chairperson. The elected chairperson and vice chairperson shall serve in these roles until their terms of appointment on the council expire.
- (d) The advisory council shall meet quarterly to review this clearinghouse of information, and may meet more often at the call of the chairperson or as determined by a majority of members.
- (e) The council members shall be appointed to 4-year terms, except that, to provide for staggered terms, one initial appointee each from the Governor, the President of the Senate, and the Speaker of the House of Representatives shall be

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appointed to a 2-year term, one appointee each from these officials shall be appointed to a 3-year term, and the remaining initial appointees shall be appointed to 4-year terms. All subsequent appointments shall be for 4-year terms. A vacancy shall be filled for the remainder of the unexpired term in the same manner as the original appointment.

- (f) Members of the council shall serve without compensation. Meetings of the council may be held in person, without reimbursement for travel expenses, or by teleconference or other electronic means.
- (g) The Department of Health shall provide administrative support for the advisory council.
- Section 2. Paragraph (c) of subsection (1) of section 391.025, Florida Statutes, is amended to read:
  - 391.025 Applicability and scope.
- (1) The Children's Medical Services program consists of the following components:
- (c) The developmental evaluation and intervention program, including the  $\underline{\text{Early Steps}}$   $\underline{\text{Florida Infants and Toddlers Early}}$   $\underline{\text{Intervention}}$  Program.
- Section 3. Subsection (19) is added to section 391.026, Florida Statutes, to read:
- 391.026 Powers and duties of the department.—The department shall have the following powers, duties, and responsibilities:
- (19) To serve as the lead agency to administer the Early

  Steps Program pursuant to part C of the federal Individuals with

  Disabilities Education Act and part III of this chapter.
- Section 4. Section 391.301, Florida Statutes, is amended to read:

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391.301 <u>Early Steps Program; establishment and goals</u>

Developmental evaluation and intervention programs; legislative findings and intent.—

- (1) The Early Steps Program is established within the department to serve infants and children who are at risk of developmental disabilities and infants and children with developmental delays by providing developmental evaluation and early intervention and by providing families with training and support services in a variety of home and community settings The Legislature finds that the high-risk and disabled newborn infants in this state need in-hospital and outpatient developmental evaluation and intervention and that their families need training and support services. The Legislature further finds that there is an identifiable and increasing number of infants who need developmental evaluation and intervention and family support due to the fact that increased numbers of low-birthweight and sick full-term newborn infants are now surviving because of the advances in neonatal intensive care medicine; increased numbers of medically involved infants are remaining inappropriately in hospitals because their parents lack the confidence or skills to care for these infants without support; and increased numbers of infants are at risk due to parent risk factors, such as substance abuse, teenage pregnancy, and other high-risk conditions.
- (2) The program must include It is the intent of the Legislature to establish developmental evaluation and early intervention services at all hospitals providing Level II or Level III neonatal intensive care services, in order to promptly identify newborns with disabilities or with conditions

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<u>associated with risks of developmental delays so</u> that families with high-risk or disabled infants may gain as early as possible the services and skills they need to support their <u>infants'</u> development <u>infants</u>.

- (3) The program must It is the intent of the Legislature that a methodology be developed to integrate information and coordinate services on infants with potentially disabling conditions with other early developmental evaluation and intervention programs, including, but not limited to, Part C of Pub. L. No. 105-17 and the Healthy Start program, the newborn screening program, and the Blind Babies Program.
  - (4) The program must:
- (a) Enhance the development of infants and toddlers with disabilities in order to mitigate any potential developmental delay.
- (b) Expand the recognition by health care providers, families, and the public of the significant brain development that occurs during a child's first 3 years of life.
- (c) Affirm the importance of the family in all areas of the child's development and to support the family's participation in early intervention services and decisions affecting the child.
- (d) Operate a comprehensive, coordinated interagency system of early intervention services and supports in accordance with part C of the federal Individuals with Disabilities Education Act.
- (e) Ensure timely evaluation, individual planning, and early intervention services necessary to meet the unique needs of eligible children.
  - (f) Build the service capacity and enhance the competencies

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of health care providers serving children with unique needs and abilities.

- (g) Ensure programmatic and fiscal accountability through establishment of a high-capacity data system, active monitoring of performance indicators, and ongoing quality improvement.
- Section 5. Section 391.302, Florida Statutes, is amended to read:
- 391.302 Definitions.—As used in ss. 391.301-391.308 ss. 391.301-391.307, the term:
- (1) "Developmental delay" means a condition, identified and measured through appropriate instruments and procedures, which may delay physical, cognitive, communication, social or emotional, or adaptive development.
- (2) "Developmental disability" means a condition, identified and measured through appropriate instruments and procedures, which may impair physical, cognitive, communication, social or emotional, or adaptive development.
- (3) "Developmental intervention" or "early intervention" means individual individualized therapies and services needed to enhance both the infant's or toddler's growth and development and family functioning. The term includes habilitative services and devices, rehabilitative services and devices, and parent support and training.
- (4) "Habilitative services and devices" means health care services and devices that help a child maintain, learn, or improve skills and functioning for daily living.
- (5) "Infant or toddler" or "child" means a child from birth until the child's third birthday.
  - (6) (3) "In-hospital intervention services" means the

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provision of assessments; the provision of <u>individual</u> individual services; monitoring and modifying the delivery of medical interventions; and enhancing the environment for the high-risk, developmentally disabled, or medically involved infant or toddler in order to achieve optimum growth and development.

- (7) "Local program office" means an office that administers the Early Steps Program within a municipality, county, or region.
- (8) (4) "Parent support and training" means a range of services to families of high-risk, developmentally disabled, or medically involved infants or toddlers, including family counseling; financial planning; agency referral; development of parent-to-parent support groups; education concerning growth, development, and developmental intervention and objective measurable skills, including abuse avoidance skills; training of parents to advocate for their child; and bereavement counseling.
- (9) "Rehabilitative services and devices" means restorative and remedial services and mechanisms that maintain or enhance the current level of functioning of a child if there is a possibility of improvement or reversal of impairment.

Section 6. Section 391.308, Florida Statutes, is amended to read:

391.308 <u>Early Steps</u> <u>Infants and Toddlers Early Intervention</u>
Program.—The <u>department shall</u> <u>Department of Health may</u> implement and administer part C of the federal Individuals with
Disabilities Education Act (IDEA), which shall be known as the <u>"Early Steps"</u> <u>"Florida Infants and Toddlers Early Intervention</u>
Program."

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(1) <u>PERFORMANCE STANDARDS.—The department shall ensure that</u> the Early Steps Program complies with the following performance standards:

- (a) The program must provide services from referral through transition in a family-centered manner that recognizes and responds to unique circumstances and needs of children and their families as measured by a variety of qualitative data, including satisfaction surveys, interviews, focus groups, and input from stakeholders.
- (b) The program must provide individual family support plans that are understandable and usable by families, health care providers, and payors and that identify the current level of functioning of the family, family supports and resources, expected outcomes, and specific early intervention services needed to achieve the expected outcomes, as measured by user feedback and periodic independent evaluation.
- (c) The program must help each family to use available resources in a way that maximizes the child's access to services necessary to achieve the outcomes of the individual family support plan, as measured by family feedback and by independent assessments of services used by each child.
- (d) The program must offer families access to quality services that effectively enable children with developmental disabilities and developmental delays to achieve optimal functional levels as measured by an independent evaluation of outcome indicators in social relationships, communication, and adaptive behaviors.
  - (2) DUTIES OF THE DEPARTMENT.—The department shall: $\tau$
  - (a) Jointly with the Department of Education, shall

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annually prepare a grant application to the United States

Department of Education for funding early intervention services
for infants and toddlers with disabilities, from birth through
36 months of age, and their families pursuant to part C of the
federal Individuals with Disabilities Education Act.

- (b) (2) The department, Jointly with the Department of Education, provide shall include a reading initiative as an early intervention service for infants and toddlers.
- (c) Annually develop a state plan for the Early Steps Program.
- 1. The plan must assess the need for early intervention services, evaluate the extent of the statewide need that is met by the program, identify barriers to fully meeting the need, and recommend specific action steps to improve program performance.
- 2. The plan must be developed through an inclusive process that involves families, local program offices, health care providers, and other stakeholders.
- (d) Ensure the provision of developmental evaluation and intervention services in each hospital that provides Level II and Level III neonatal intensive care services to an infant or a toddler identified as being at risk for developmental disabilities or identified as medically involved who, along with his or her family, would benefit from early intervention services.
- (e) Establish standards and qualifications for developmental evaluation and early intervention service providers, including standards for determining the adequacy of provider networks in each local program office service area.
  - (f) Establish statewide uniform protocols and procedures to

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determine eligibility for developmental evaluation and early intervention services.

- (g) Establish a consistent, statewide format and procedure for preparing and completing an individual family support plan.
- (h) Promote interagency cooperation and coordination,
  particularly with the Medicaid program and the Department of
  Education program pursuant to part B of the federal Individuals
  with Disabilities Education Act.
- 1. Coordination with the Medicaid program shall be developed and maintained through written agreements with the Agency for Health Care Administration and Medicaid managed care entities as well as through active and ongoing communication with these entities. The department shall assist local program offices to negotiate agreements with Medicaid managed care entities in the service areas of the local program offices.
- 2. Coordination with education programs pursuant to part B of the federal Individuals with Disabilities Education Act shall be developed and maintained through written agreements with the Department of Education. The department shall assist local program offices to negotiate agreements with school districts in the service areas of the local program offices.
- (i) Develop and disseminate the knowledge and methods necessary to effectively coordinate benefits among various payor types.
- (j) Provide an appeals process under chapter 120 for applicants found ineligible for developmental evaluation or early intervention services or denied financial support for such services.
  - (k) Competitively procure local program offices to provide

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services throughout the state in accordance with chapter 287.

The department shall specify the requirements and qualifications for local program offices in the procurement document.

- (1) Establish performance standards and other metrics for evaluation of local program offices, including standards for measuring timeliness of services, outcomes of early intervention services, and administrative efficiency.
- $\underline{\mbox{(m) Provide technical assistance to the local program}}$  offices.
- (3) ELIGIBILITY.—The department shall apply the following eligibility criteria as authorized in the General Appropriations Act.
- (a) All children in this state are eligible for an evaluation to determine the presence of a developmental disability or conditions that cause or increase the risk of developmental delays.
- (b) All children determined to have a developmental disability based on an established condition or determined to be at risk of developmental delays based on an informed clinical opinion are eligible for Early Steps Program services.
- (c) A child is eligible for Early Steps Program services if the application of a standardized evaluation instrument results in a score that is 1.5 standard deviations from the mean in two or more of the following domains: physical, cognitive, communication, social or emotional, and adaptive.
- (d) A child is eligible for Early Steps Program services if the application of a standardized evaluation instrument results in a score that is 2.0 standard deviations from the mean in one of the following domains: physical, cognitive, communication,

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social or emotional, and adaptive.

(e) A child is eligible for Early Steps Program services if diagnosed with a physical or mental condition that has a high probability of resulting in a developmental delay.

- (4) DUTIES OF THE LOCAL PROGRAM OFFICES.—A local program office shall:
- (a) Evaluate a child to determine eligibility within 45 calendar days after the child is referred to the program.
- (b) Notify the parent or legal guardian of his or her child's eligibility status initially and at least annually thereafter. If a child is determined not to be eligible, the local program office must provide the parent or legal guardian with written information on the right to an appeal and the process for making such an appeal.
- (c) Secure and maintain interagency agreements or contracts with local school districts and the Medicaid managed care plans in a local service area.
- (d) Provide services directly or procure services from health care providers that meet or exceed the minimum qualifications established for service providers. The local program office must become a Medicaid provider if it provides services directly.
- (e) Provide directly or procure services that are, to the extent possible, delivered in a child's natural environment, such as in the child's home or community setting. The inability to provide services in the natural environment is not a sufficient reason to deny services.
- (f) Develop an individual family support plan for each child served. The plan must:

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1. Be completed within 45 calendar days after enrollment in the program;

- 2. Be developed in conjunction with the child's parent or legal guardian who provides written consent for the services included in the plan;
- 3. Be reviewed at least annually with the parent or legal guardian and updated if needed; and
- 4. Include steps to transition to school or other future services by the child's third birthday.
- (g) Assess the progress of the child and his or her family in meeting the goals of the individual family support plan.
- (h) For each service required by the individual family support plan, refer the child to an appropriate service provider or work with Medicaid managed care entities or private insurers to secure the needed services.
- (i) Provide care coordination services, including contacting the appropriate service provider to determine whether the provider can timely deliver the service, providing the parent or legal guardian with the name and location of the service provider and the date of any appointment made on behalf of the child, and contacting the parent or legal guardian after the service is provided to ensure that the service is delivered timely and to determine whether additional services are needed.
- (j) Negotiate and maintain agreements with Medicaid providers and Medicaid managed care entities in its area.
- 1. With the parent's or legal guardian's permission, the services in the child's approved individual family support plan shall be communicated to the Medicaid managed care entity.

  Services that cannot be funded by Medicaid must be specifically

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identified and explained to the family.

- 2. The agreement between the local program office and Medicaid managed care entities must establish methods of communication and procedures for the timely approval of services covered by Medicaid.
- (k) Develop agreements and arrangements with private insurers in order to coordinate benefits and services for any mutual enrollee.
- 1. The child's approved individual family support plan may be communicated to the child's insurer with the parent's or legal guardian's permission.
- 2. The local program office and private insurers shall establish methods of communication and procedures for the timely approval of services covered by the child's insurer, if appropriate and approved by the child's parent or legal guardian.
- (1) Provide to the department data necessary for an evaluation of the local program office performance.
- (5) ACCOUNTABILITY REPORTING.—By October 1 of each year, the department shall prepare and submit a report that assesses the performance of the Early Steps Program to the Governor, the President of the Senate, the Speaker of the House of Representatives, and the Florida Interagency Coordinating Council for Infants and Toddlers. The department must address the performance standards in subsection (1) and report actual performance compared to the standards for the prior fiscal year. The data used to compile the report must be submitted by each local program office in the state. The department shall report on all of the following measures:

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- (a) Number and percentage of children served.
- (b) Number and percentage of children demonstrating improved social or emotional skills after the program.
- (c) Number and percentage of children demonstrating improved use of knowledge and cognitive skills after the program.
- (d) Number and percentage of families reporting positive outcomes in the development of children as a result of early intervention services.
- (e) Progress toward meeting the goals of individual family support plans.
  - (f) Any additional measures established by the department.
- (6) STATE INTERAGENCY COORDINATING COUNCIL.—The Florida
  Interagency Coordinating Council for Infants and Toddlers shall
  serve as the state interagency coordinating council required by
  34 C.F.R. s. 303.600. The council shall be housed for
  administrative purposes in the department, and the department
  shall provide administrative support to the council.
  - (7) TRANSITION TO EDUCATION.—
- (a) At least 6 months before a child reaches 3 years of age, the local program office shall:
- 1. Initiate transition planning to ensure the child's successful transition from the Early Steps Program to a school district program for children with disabilities or to another program as part of an individual family support plan.
- 2. Notify the appropriate local school district located in its service area that the child may be eligible for specialized instruction or related services as determined by the local school district pursuant to ss. 1003.21 and 1003.57.

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(b) The local program office shall convene a transition conference that includes participation by a local school district representative and a child's parent or legal guardian to discuss options for and availability of services at least 3 months before the child reaches 3 years of age.

- (c) The local school district shall evaluate and determine a child's eligibility for receiving specialized instruction or related services pursuant to ss. 1003.21 and 1003.57.
- (d) The local program office, in conjunction with the local school district, shall modify a child's individual family support plan, or, if applicable, the local school district shall develop an individual education plan for the child pursuant to ss. 1003.57, 1003.571, and 1003.5715, which identifies specialized instruction or related services that the child will receive and the providers or agencies that will provide such services.
- (e) If a child is determined to be ineligible for school district program services, the local program office shall provide the child's parent or legal guardian with written information on other available services or community resources.
- (f) The local program office shall negotiate and maintain an interagency agreement with each local school district in its service area pursuant to the federal Individuals with

  Disabilities Education Act, 20 U.S.C. s. 1435(a)(10)(F). Each interagency agreement must be reviewed at least annually and updated upon review, if needed.

Section 7. Subsections (1) and (2) of section 413.092, Florida Statutes, are amended to read:

413.092 Blind Babies Program. -

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(1) The Blind Babies Program is created within the Division of Blind Services of the Department of Education to provide community-based early-intervention education to children from birth through 5 years of age who are blind or visually impaired, and to their parents, families, and caregivers, through community-based provider organizations. The division shall enlist parents, ophthalmologists, pediatricians, schools, the Early Steps Program Infant and Toddlers Early Intervention Programs, and therapists to help identify and enroll blind and visually impaired children, as well as their parents, families, and caregivers, in these educational programs.

(2) The program is not an entitlement but shall promote early development with a special emphasis on vision skills to minimize developmental delays. The education shall lay the groundwork for future learning by helping a child progress through normal developmental stages. It shall teach children to discover and make the best use of their skills for future success in school. It shall seek to ensure that visually impaired and blind children enter school as ready to learn as their sighted classmates. The program shall seek to link these children, and their parents, families, and caregivers, to other available services, training, education, and employment programs that could assist these families in the future. This linkage may include referrals to the school districts and the Early Steps Infants and Toddlers Early Intervention Program for assessments to identify any additional services needed which are not provided by the Blind Babies Program. The division shall develop a formula for eligibility based on financial means and may create a means-based matrix to set a copayment fee for families

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having sufficient financial means.

Section 8. Subsection (1) of section 1003.575, Florida Statutes, is amended to read:

1003.575 Assistive technology devices; findings; interagency agreements. - Accessibility, utilization, and coordination of appropriate assistive technology devices and services are essential as a young person with disabilities moves from early intervention to preschool, from preschool to school, from one school to another, and from school to employment or independent living. If an individual education plan team makes a recommendation in accordance with State Board of Education rule for a student with a disability, as defined in s. 1003.01(3), to receive an assistive technology assessment, that assessment must be completed within 60 school days after the team's recommendation. To ensure that an assistive technology device issued to a young person as part of his or her individualized family support plan, individual support plan, or an individual education plan remains with the individual through such transitions, the following agencies shall enter into interagency agreements, as appropriate, to ensure the transaction of assistive technology devices:

(1) The <u>Early Steps</u> <del>Florida Infants and Toddlers Early</del> <del>Intervention</del> Program in the Division of Children's Medical Services of the Department of Health.

Interagency agreements entered into pursuant to this section shall provide a framework for ensuring that young persons with disabilities and their families, educators, and employers are

informed about the utilization and coordination of assistive

technology devices and services that may assist in meeting transition needs, and shall establish a mechanism by which a young person or his or her parent may request that an assistive technology device remain with the young person as he or she moves through the continuum from home to school to postschool.

Section 9. Section 391.303, Florida Statutes, is repealed.
Section 10. Section 391.304, Florida Statutes, is repealed.
Section 11. Section 391.305, Florida Statutes, is repealed.
Section 12. Section 391.306, Florida Statutes, is repealed.
Section 13. Section 391.307, Florida Statutes, is repealed.
Section 14. This act shall take effect July 1, 2016.

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