Independent Living

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Outcomes

• Primary Outcomes
  • Individuals with Spina Bifida:
    • Achieve optimal independence in self-management, independent living, and employment as well as maximal participation in society within their capabilities.
    • Develop autonomy, responsibility, and self-management.

• Secondary Outcomes
  • Develop self-regulation and adequate executive functioning skills.
  • Engage in a variety of age appropriate social activities.

• Tertiary Outcomes
  • Receive adequate information and supportive services concerning health care, school, and environment.
  • Interact effectively with family, health care providers and others in the external environment.
Prenatal/Infancy (through age 1 year)

• Clinical Question
  • What is the evidence about the best ways to foster independence in toddlers with disabilities?

• Guidelines:
  1. Provide anticipatory guidance regarding developmental needs of children (such as exploration of environment, routines, and age-appropriate choices).
  2. Teach families to offer daily age-appropriate choices such as choice between two articles of clothes, two cereals for breakfast, and two books to read, etc.
  3. Encourage families to expect participation in daily life activities, including such things as picking up toys, cleaning up, and imitative housework.
  4. In all children autonomy and independence is fostered by opportunity to make choices and to develop a sense of mastery.
Toddler (1-3 years)

• Clinical Questions
  • Same as infancy

• Guidelines
  • Same as infancy
Preschool (3-5 years)

• Clinical Question
  • What evidence exists about the best way to foster independence in preschoolers with disabilities?

• Guidelines:
  1. Identify and refer to community resources which promote independence such as early education programs.
  2. Expand range of daily life activities and chores
School Age

• Clinical Questions:
  • What is the most effective way to teach independent self-care in school age children with spina bifida?
  • What are optimal age expectations for self-care in school age children with spina bifida?

• Guidelines:
  1. Teach child self-care skills, including skills to prevent secondary conditions (CIC, skin care, equipment care, bowel and bladder care, wheelchair maintenance and propulsion).
  2. Serve as a resource to school systems regarding transportation, learning skills, health issues, and development of self-care skills.
  3. Expand range of daily life activities and chores.
  5. Assess peer relationships and encourage peer involvement.
  6. Progressively expect the child to organize school work and activities.
  7. Teach money management.
  8. Set beginning expectations for independent living.
Teenage

Clinical Questions:
- What is the most effective way to manage the transition to adult health care?
- What behaviors are required to negotiate the adult health care world?
- What behaviors predict independence in adulthood?

Guidelines:
1. Evaluate self-care in activities of daily living, skin care, equipment care, and bowel and bladder care, ability to make health care appointments.
2. Evaluate and monitor cognitive functions as they underpin decision-making, self-management, socialization, and transition issues.
3. Encourage participation in IEP planning that addresses transition skills (mandated at age 14).
4. Assess individual and system barriers to transition from pediatric to adult health care (e.g., responsibility for health management, advocacy, assertiveness, and insufficient adult services).
Teenage

• Guidelines continued:
  5. Assess ability to use transportation; encourage enrollment in driver’s education, (adaptive) if the teen possesses cognitive/motor abilities.
  6. Discuss sexuality, contraception (including latex allergy precautions), marriage, childbearing issues, genetic counseling, folic acid supplementation and latex allergy.
  7. Expand interventions aimed at all activities of daily living including money management.
  8. Involve the Department of Vocational Rehabilitation (Access VR), vocational counseling in transition team planning.
  9. Expand range of responsibilities for daily life activities, chores, and jobs.
10. Progress expectations for independent living
Adult

• Clinical Questions:
  • What behaviors lead to self-management and independence in adults with spina bifida?
  • What behaviors or supports lead to positive health outcomes in adults with spina bifida?

• Guidelines:
  1. Evaluate and monitor cognitive functions as they underpin decision making, self-management, employment, independent living, and socialization.
  2. Provide information about accessible housing, financing, outside agencies.
  4. Expand discussion of sexuality, contraception (including latex allergy precautions), marriage, childbearing issues, genetic counseling, folic acid supplementation and latex allergy.
  5. Expand on child rearing issues/parenting as appropriate.
  6. Encourage involvement of empowerment activities include SBA.
  7. Assure continuity of primary health care and continued access to comprehensive and coordinated specialty care.
  8. Encourage mentoring for teens with Spina Bifida.
Research Gaps

• What are the barriers and facilitators to developing autonomy, self-management and independent living for people with spina bifida?

• What successful strategies can health care workers use to facilitate behaviors that encourage independence in children and adults with spina bifida and their parents?

• What supports lead to positive health outcomes for children and adults with spina bifida and their parents?
References

• http://www.tats.ucf.edu/docs/eUpdates/Curriculum-14.pdf
References

