



**BIBLIOGRAPHY
TRANSITION TO ADULTHOOD
WITH EMPHASIS ON
HEALTH TRANSITION**

November 2009

Whole issues of journals devoted to transition, disabilities, or adolescent health:

Child: Care, Health and Development, 2008, September, Volume 34 (5)

Family and Community Health, 2006, 29, January-March, Supplement 1

Journal of Adolescent Health, 1995, January, Volume 17 (1)

Journal of Behavioral Health Services and Research, 2008, October, Volume 35(4)

International Journal of Adolescent Medicine and Health, 2007, July-September, Volume 19 (3)

Medical Journal of Australia, 2007, October 1, Volume 187 (7 Suppl)

New Directions in Youth Development, 2007, Spring, Volume 113

Nursing Clinics of North America

2007, December: Sexuality and Chronic Illness: Assessment and Interventions, Volume 42 (4)

2004 December: Transition Care Issues for the Adolescent with Congenital Heart Disease, Volume 39 (4)

2003, June: Developmental Disabilities, Volume 38 (2)

2002, September: Adolescent Health, Volume 37 (3)

Pediatric Blood and Cancer, 2008, May, Volume 50 (5 Suppl)

Physical and Occupational Therapy in Pediatrics, 2006, Volume 26(4)

Progress in Transplantation, 2006, Volume 16(4)

Abbott S, Cairns L & Davies H (2008) Empowering young people with long-term illness. *Paediatr Nursing*, 20(4), 35-7

Abramson N (1996) Quality of life: Who can make the judgment? *American Journal of Medicine*, 100(3), 365-366

ACRM Committee on Social, Ethical, and Environmental Aspects of Rehabilitation (1993) Addressing the post-rehabilitation health care needs of persons with disabilities. *Archives of Physical Medicine and Rehabilitation*, (74:S), 8-14

Admi H & Shaham B (2007) Living with epilepsy: Ordinary people coping with extraordinary situations. *Qual Health Res.*, 17(9), 1178-87

Ahrens KR, DuBois DL, Richardson LP, Fan MY & Lozano P (2008) Youth in foster care with adult mentors during adolescence have improved adult outcomes. *Pediatrics*, 21(2), e246-52

Ailey SH, Marks BA, Crisp C & Hahn JE (2003) Promoting sexuality across the life span for individuals with intellectual and developmental disabilities. *Nursing Clinics of North America*, 33 (2), 229-52

Akeson N, Worth A & Sheikh A (2007) The psychosocial impact of anaphylaxis on young people and their parents. *Clin Exp Allergy*, 37(8), 1213-20

Akinbami LJ, Gandhi H & Cheng TL (2003) Availability of adolescent health services and confidentiality in primary care practices. *Pediatrics*, 111(2), 394-401

Albrecht GL & Devlieger PJ (1999) The disability paradox: High quality of life against all odds. *Social Science and Medicine*, 48(8), 977-988

- Albritton KH & Eden T** (2008) Access to care. *Pediatr Blood Cancer*, 50(5 Suppl), 1094-8
- Alderman EM, Rieder J & Cohen MI** (2003) The history of adolescent medicine. *Pediatric Research*, 54, (1), 137-147
- Alexander B & Schrauben S** (2006) Outside the margins: Youth who are different and their special health care needs. *Primary Care*, 33(2), 285-303
- Alexander J, Callahan B, King A, King J, Hooper S & Bartel S** (2001) North Carolina's TBI Project ACCESS. Assuring coordinated care, education, and support for survivors of pediatric brain injury. *N C Med J*, 62, 359-63
- Allen D & Gregory J** (2009) The transition from children's to adult diabetes services: Understanding the 'problem'. *Diabet Med*, 26(2), 162-6
- Allen DB** (1999) Issues in the transition from childhood to adult growth hormone therapy. *Pediatrics*, 104, 1004-1009
- Al Mamun A, Cramb S, McDermott BM, O'Callaghan M, Najman JM & Williams GM** (2007) Adolescents' perceived weight associated with depression in young adulthood: A longitudinal study. *Obesity (Silver Spring)*, 15(12), 3097-105
- Alpay H** (2009) Transition of the adolescent patient to the adult clinic. *Perit Dial Int*, 29, Feb, Suppl 2, S180-2
- American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP), American College of Physicians (ACP), American Osteopathic Association (AOA)** (2007) Joint Principles of the Patient-Centered Medical Home. Available at <http://www.pcpcc.net/node/14>
- American Academy of Pediatrics** (2004) The medical home. *Pediatrics*, 113, Supplement (5), 1471-1548
- American Academy of Pediatrics** (1996) Transition of care provided for adolescents with special health care needs. American Academy of Pediatrics Committee on Children with Disabilities and Committee on Adolescence. *Pediatrics*, 98 (6, Pt 1), 1203-1206
- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine** (2002) A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110, 1304-1306, available at <http://pediatrics.aappublications.org/cgi/reprint/110/6/S1/1304.pdf>
- American Academy of Pediatrics Committee on Child Health Financing** (1995) Guiding principles for managed care arrangements for the health care of infants, children, adolescents, and young adults. *Pediatrics*, 95(4), 613-615
- American Academy of Pediatrics Committee on Children with Disabilities** (2002) The role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. *Pediatrics*, 106, 854-856
- American Academy of Pediatrics Committee on Children with Disabilities** (1999) Care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs. *Pediatrics*, 104, 978-981
- American Medical Association, Council on Scientific Affairs** (1993) The health care of children and youths with disabilities. *Archives of Family Medicine*, 2, 326-329
- Anderson BJ & Wolpert HA** (2004) A developmental perspective on the challenges of diabetes education and care during the young adult period. *Patient Education and Counseling*, 53, 347-52
- Anderson CJ, Johnson KA, Klaas SJ & Vogel, LC** (1998) Pediatric spinal cord injury: Transition to adulthood. *Journal of Vocational Rehabilitation*, 10, 103-113
- Anderson CJ, Vogel LC, Willis KM & Betz RR** (2006) Stability of transition to adulthood among individuals with pediatric-onset spinal cord injuries. *J Spinal Cord Med.*, 29 (1), 46-56
- Anderson DL, Flume PA, Hardy KK & Gray S** (2002) Transition programs in cystic fibrosis centers: Perceptions of patients. *Pediatric Pulmonology*, 33, 327-331

Anderson EM, Clark L & Spain B (1982) *Disability in Adolescence*. New York: Methuen and Company

Anderson G & Knickman JR (2001) Changing the chronic care system to meet people's needs. *Health Affairs*, 20 (6), 146-60

Andersson C & Mattsson E (2001) Adults with cerebral palsy: A survey describing problems, needs, and resources, with special emphasis on locomotion. *Developmental Medicine and Child Neurology*, 43, 76-82

Andren E (2000) Dependence and perceived difficulty in activities of daily living in adults with cerebral palsy and spina bifida. *Disabil Rehabil*, 22, 299-307

Anie KA & Telfair J (2005) Multi-site study of transition in adolescents with sickle cell disease in the United Kingdom and the United States. *International Journal of Adolescent Medicine and Health*, 17 (2), 169-178

Annunziato RA, Emre S, Shneider B, Barton C, Dugan CA & Shemesh E (2007) Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatr Transplant.*, 11(6), 608-14

Annunziato RA, Emre S, Shneider BL, Dugan CA, Aytaman Y, McKay MM & Shemesh E (2008) Transitioning health care responsibility from caregivers to patient: A pilot study aiming to facilitate medication adherence during this process. *Pediatr Transplant*, 12(3), 309-15

Ansell BM & Chamberlain MA (1998) Children with chronic arthritis: The management of transition to adulthood. *Bailliere's Clinical Rheumatology*, 12(2), 363-374

Anthony SJ, Martin K, Drabble A, Seifert-Hansen M, Dipchand AI & Kaufman M (2009) Perceptions of transitional care needs and experiences in pediatric heart transplant recipients. *Am J Transplant*, 9(3), 614-9; erratum in: *Am J Transplant*, 9(7), 1698

Antle BJ, Montgomery G & Stapleford C (2009) The many layers of social support: Capturing the voices of young people with spina bifida and their parents. *Health Soc Work*. 34(2), 97-106

Appleton RE (2001) Transition from paediatric clinic to the adult service. *J R Soc Med*, 94, 554

Appleton RE, Chadwick D & Sweeny A (1997) Managing the teenager with epilepsy: Paediatric to adult care. *Seizure*, 6, 27-30

Arcelus J, Bouman WP & Morgan JF (2008) Treating young people with eating disorders: Transition from child mental health to specialist adult eating disorder services. *Eur Eat Disord Rev.*, 16(1), 30-6

Armstrong KH, Dedrick RF & Greenbaum PE (2003) Factors associated with community adjustment of young adults with serious emotional disturbance: A longitudinal analysis. *Journal of Emotional and Behavioral Disorders*, 11, 66-76

Arnett JJ (2004) *Emerging adulthood: The winding road from late teens through the twenties*. Oxford University Press

Arnett JJ (2003) Conceptions of the transition to adulthood among emerging adults in American ethnic groups. *New Dir Child Adolesc Dev*, 100 (Summer), 63-75

Arnett JJ (2000) Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480

Aung TS, Boughey A & Ward AB (1994) A study of the North Staffordshire young adult service for the physically handicapped school leaver and young adult. *Clinical Rehabilitation*, 8, 247- 252

Avenevoli S & Steinberg L (2001) The continuity of depression across the adolescent transition. *Adv Child Dev Behav.*, 28, 139-173

Ayala GX, Miller D, Zagami E, Riddle C, Willis S & King D (2006) Asthma in middle schools: What students have to say about their asthma. *Journal of School Health*, 76(6), 208-14

Bailey S, O'Connell B & Pearce J (2003) The transition from paediatric to adult health care services for young adults with a disability: An ethical perspective. *Aust Health Rev*, 26(1), 64-69

Baker CP, Rosenberg M, Mossberg KA, Holzer C 3rd, Blakeney P, Robert R, Thomas C & Meyer W 3rd (2008) Relationships between the Quality of Life Questionnaire (QLQ) and the SF-36 among young adults burned as children. *Burns*. 34 (8), 1163-1168

Baker CP, Russell WJ, Meyer W 3rd & Blakeney P (2007) Physical and psychologic rehabilitation outcomes for young adults burned as children. *Arch Phys Med Rehabil.*, 88(12 Suppl 2), S57-64

Baker GA, Hargis E, Hsieh MM, Mounfield H, Arzimanoglou A, Glauser T, Pellock J, Lund S; International Bureau for Epilepsy (2008) Perceived impact of epilepsy in teenagers and young adults: An international survey. *Epilepsy Behav*, 12(3), 395-401

Baker KL & Coe LM (1993) Growing up with a chronic condition: Transition to young adulthood for the individual with cystic fibrosis. *Holistic Nursing Practice*, 8, 8-15

Baldassano R, Ferry G, Griffiths A, Mack D, Markowitz J & Winter HJ (2002) Transition of the patient with inflammatory bowel disease from pediatric to adult care: Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *Pediatr Gastroenterol Nutr*, 34, 245-8

Balon YE, Then KL, Rankin JA & Fung T (2008) Looking beyond the biophysical realm to optimize health: Results of a survey of psychological well-being in adults with congenital cardiac disease. *Cardiol Young*, 18(5), 494-501

Barbero G (1982) Leaving the pediatrician for the internist. *Annals of Internal Medicine*, 96(1), 673-674

Barf HA, Post MW, Verhoef M, Jennekens-Schinkel A, Gooskens RH & Prevo AJ (2007) Life satisfaction of young adults with spina bifida. *Dev Med Child Neurol*, 49(6), 458-63

Barker G, Olukoya A & Aggleton P (2005) Young people, social support and help-seeking. *Int J Adolesc Med Health*, 17(4), 315-35

Barnhart RC (2001) Aging adult children with developmental disabilities and their families: Challenges for occupational therapists and physical therapists. *Physical and Occupational Therapy in Pediatrics*, 21(4), 69-81

Bartman B, Moy E & D'Angelo L (1997) Access to ambulatory care for adolescents: The role of a usual source of care. *J Health Care Poor Underserved*, 8, 214-226

Baskin ML, Collins MH, Brown F, Griffith JR, Samuels D, Moody A, Thompson MP, Eckman J & Kaslow NJ (1998) Psychosocial considerations in sickle cell disease (SCD): The transition from adolescence to young adulthood. *Journal of Clinical Psychology in Medical Settings*, 5 (3), 315-341

Bates K, Bartoszesky L & Friedland A (2003) As the child with chronic disease grows up: Transitioning adolescents with special health care needs to adult-centered health care. *Delaware Medical Journal*, 75 (6), 217-220

Bauermeister JA, Zimmerman MA, Barnett TE & Caldwell CH (2007) Working in high school and adaptation in the transition to young adulthood among African American youth. *Journal of Youth and Adolescence*, 36 (7), 877-890

Bax MC, Smyth DP & Thomas A (1988) Health care of physically handicapped young adults. *British Medical Journal*, 296, 1153-5

Bazyk S (2005) Exploring the development of meaningful work for children and youth in Western contexts. *Work*, 24(1), 11-20

Beale IL, Kato PM, Marin-Bowling VM, Guthrie N & Cole SW (2007) Improvement in cancer-related knowledge following use of a psychoeducational video game for adolescents and young adults with cancer. *Journal of Adolescent Health*, 41(3), 263-70

Beck KS & Newman SS (1999) Summary of data on young people with disabilities in the United States. Conwal Incorporated and distributed at the President's Task Force on Employment of People with Disabilities meeting in Washington, DC, July

Beck MJ, Evans BJ, Quarry-Horn JL & Kerrigan JR (2002) Type 2 Diabetes Mellitus: Issues for the medical care of pediatric and adult patients. *Southern Medical Journal*, 95, 992-1000

Beers NS, Kemeny A, Sherritt L & Palfrey JS (2003) Variations in state-level definitions: Children with special health care needs. *Public Health Reports*, 118, 434-447

- Bell L** (2007) Adolescent dialysis patient transition to adult care: A cross-sectional survey. *Pediatr Nephrol*, 22(5), 720-6
- Bell LE, Bartosh SM, Davis CL, Dobbels F, Al-Uzri A, Lotstein D, Reiss J & Dhamidharka VR** (2008) Adolescent transition to adult care in solid organ transplantation: A consensus conference report. *Am J Transplant*, 8(11), 2230-42
- Bell S & Lee C** (2008) Transitions in emerging adulthood and stress among young Australian women. *Int J Behav Med*, 15(4), 280-8
- Bellin M, Sawin KJ, Roux G, Buran CF, Brei TJ & Kain J** (2007) The experience of being adolescent women with a disability, Part 1: Self esteem and family relationships. *Rehabilitation Nursing*, 32 (1), 57-67
- Belling L, Harrop M, Kocik S, Obstein L, Standish D, Vlasich W & Zappa S** (2003) Transition guidelines for people with bleeding orders. *HEMAware*, 8 (4), 88-95
- Bennett DL, Towns SJ & Steinbeck KS** (2005) Smoothing the transition to adult care: The most important need is for a change of attitude and approach. *Med J Aust*, 182(8), 373-4
- Bent N, Tennant A, Swift T, Posnett J, Scuffham P & Chamberlain MA** (2002) Team approach vs. ad hoc health services for young people with physical disabilities: A retrospective cohort study. *Lancet*, 360, 1280-86
- Beresford B** (2004) On the road to nowhere? Young disabled people and transition. *Child Care Health Development*, 30(6), 581-7
- Beresford B & Sloper P** (2003) Chronically ill adolescents' experiences of communicating with doctors: A qualitative study. *J Adolesc Health*, 33, 172-179
- Berg SK & Hertz PG** (2007) Outpatient nursing clinic for congenital heart disease patients: Copenhagen Transition Program. *J Cardiovasc Nursing*, 2(6), 488-92
- Berge J M, Patterson JM, Goetz D & Milla C** (2007) Gender differences in young adults' perceptions of living with cystic fibrosis during the transition to adulthood: A qualitative investigation. *Families, Systems, & Health*, 25(2), 190-203
- Berkowitz S** (2009) Transitioning adolescents to adult care: Putting theory into practice. *Minn Med*, 92(3), 42-4
- Bernheimer LP, Keogh BK & Guthrie D** (2006) Young children with developmental delays as young adults: Predicting developmental and personal-social outcomes. *Am J Ment Retard*, 111(4), 263-72
- Berry D** (2004) The relationship between depression and emerging adulthood: Theory generation. *ANS Advances in Nursing Science*, 27(1), 53-69
- Bethell CD, Read D, Blumberg SJ & Newacheck PW** (2008) What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal Child Health Journal*, 12 (1), 1-14
- Betz CL** (2008) Health care transitions of youth with special health care needs: The never ending journey. *Commun Nurs Res*, 41 (Spring), 13-29
- Betz CL** (2007) Facilitating the transition of adolescents with developmental disabilities: Nursing practice issues and care. *J Pediatric Nursing*, 22(2), 103-15
- Betz CL** (2006) Examining the status of special education students: Implications for pediatric nurses. *J Pediatric Nursing*, 21(1), 1-3
- Betz, CL** (2006) Self-management and adherence of children and youth with special health care needs: Implications for pediatric nursing practice. *J Pediatric Nursing*, 21(4), 253-5
- Betz CL** (2004) Adolescents in transition of adult care: Why the concern? *Nursing Clinics of North America*, 39(4, Dec), 681-713
- Betz CL** (2004) Transition of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, 27, 179-241
- Betz CL** (2003) Nurse's role in promoting health transitions for adolescents and young adults with developmental disabilities. *Nursing Clinics of North America*, 38(2), 271-89

- Betz CL** (2001) Use of 504 plans for children and youth with disabilities: Nursing application. *Pediatric Nursing*, 27 (4), 347-352
- Betz CL** (2000) California Healthy and Ready to Work: Transition health care guide: Developmental guidelines for teaching health care. *Issues in Comprehensive Pediatric Nursing*, 23, 203-244
- Betz CL** (1999) Adolescents with chronic conditions: Linkages to adult service systems. *Pediatric Nursing*, 25 (5), 473-476
- Betz CL** (1999) Collaborative partnerships: Building new programs and services for children. *Journal of Pediatric Nursing*, 14 (5), 279-280
- Betz CL** (1998) Adolescent transitions: A nursing concern. *Pediatric Nursing*, 24 (1), 23-28
- Betz CL** (1998) Facilitating the transition of adolescents with chronic conditions from pediatric to adult health care and community settings. *Issues in Comprehensive Pediatric Nursing*, 21(2), 97-115
- Betz CL** (1998) 504 Referrals: An underutilized resource for students with special health care needs. *Journal of Pediatric Nursing*, editorial, 13 (6)
- Betz CL, Baer MT, Poulsen M, Vahanvaty U, Bare M, Haddad Y & Nwachuken G** (2004) Secondary analysis of primary and preventive services accessed and perceived service barriers by children with developmental disabilities and their families. *Issues in Comprehensive Pediatric Nursing*, 27 (2), 83-106
- Betz C, Cowell J, Craft-Rosenberg M, Krajicek M & Lobo M** (2007) Health care quality and outcome guidelines for nursing of children and families: Implications for pediatric nurse practitioner practice, research, and policy. *Journal of Pediatric Health Care*, 21 (1), 64 - 66
- Betz CL & Nehring W** (Eds.) (2007) *Promoting Health Care Transitions for Adolescents with Special Health Care Needs and Disabilities*. Baltimore, MD: Paul H. Brookes
- Betz CL & Redcay G** (2005) An exploratory study of future plans and extracurricular activities of transition age-youth and young adults. *Issues Comprehensive Pediatric Nursing*, 28 (1), 33-61
- Betz CL & Redcay G** (2005) Dimensions of the transition service coordinator role. *Journal of Specialty Pediatric Nursing*, 10 (2, Apr-Jun), 49-59
- Betz CL & Redcay G** (2003) Creating Healthy Futures: An innovative nurse-managed transition clinic for adolescents and young adults with special health care needs. *Pediatric Nursing*, 29(1), 25-30
- Betz CL & Redcay G** (2002) Lessons learned from providing transition services to adolescents with special health care needs. *Issues Comprehensive Pediatric Nursing*, 25 (2), 129-49
- Betz CL, Redcay G & Tan S** (2003) Self-reported health care self-care needs of transition-aged youth: A pilot study. *Issues in Comprehensive Pediatric Nursing*, 26, 159-181
- Bhakta BB, Rooney CM, Sat W, Roussonis SH & Chamberlain MA** (2000) Transition from paediatric to adult care. *Arch. Dis Child*, 82, 266
- Biddle L, Donovan J, Sharp D & Gunnell D** (2007) Explaining non-help-seeking amongst young adults with mental distress: A dynamic interpretive model of illness behaviour. *Social Health Illn*, 29(7), 983-1002
- Binks JA, Barden WS, Burke TA & Young, NL** (2007) What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabilitation*, 88(8), 1064-73
- Bjarnason DS** (2002) New voices in Iceland. Parents and adult children: Juggling supports and choices in time and space. *Disability & Society*, 17(3), 307-326
- Bjornsen KD** (2004) Health care transition in congenital heart disease: The providers' view point. *Nursing Clinics of North America*, 39(4), 715-26
- Blacher J** (2001) Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, 106, 173-188

- Blackorby J & Wagner M** (1996) Longitudinal postschool outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children*, 62, 399-413
- Blaisdell CJ** (2002) The adolescent with asthma: Strategies for improved outcomes. *MD Med*, 3(3), 42-4
- Blake KD, Salem-Hartshorne N, Daoud MA & Gradstein J** (2005) Adolescent and adult issues in CHARGE syndrome. *Clin Pediatr*, 44(2), 151-9
- Blalock G** (1996) Community transition teams as the foundation for transition services for youth with disabilities. *Journal of Learning Disabilities*, 29, 148-159
- Bleyer A** (2007) Adolescent and young adult (AYA) oncology: The first A. *Pediatr Hematol Oncol*, 24(5), 325-36
- Bleyer A** (2007) Young adult oncology: The patients and their survival challenges. *CA Cancer J Clin*, 57(4), 242-55
- Blomquist KB** (2007) Health and independence of young adults with disabilities: Two years later. *Orthopaedic Nursing*, 26(5), 296-309
- Blomquist KB** (2006) Healthy and Ready to Work – Kentucky: Incorporating transition into a state program for children with special health care needs. *Pediatric Nursing*, 32 (6), 515-528
- Blomquist KB** (2006) Health, education, work and independence of young adults with disabilities. *Orthopaedic Nursing*, 25 (3), 168-87
- Blomquist KB, Brown G, Peersen A & Presler EP** (1998) Transitioning to independence: Challenges for young people with disabilities and their caregivers. *Orthopaedic Nursing*, 17 (3), 27-35
- Blue-Banning M, Turnbull AP, & Pereira L** (2002) Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research and Practice for Persons with Severe Disabilities*, 27(3), 204-219
- Blum RW** (2002) Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. *Pediatrics*, 110, 1301–1303
- Blum RW** (1995) Transition to adult care: Setting the stage. *Journal of Adolescent Health*, 17, 3-5
- Blum RW** (1995) Summary of conference recommendation. Moving on: Transition from pediatric to adult health care. *Adolescent Health*, 17, 6-9
- Blum RW** (1994) Executive summary and recommendations. *Journal of School Health*, 64 (6), 221-222
- Blum RW** (1991) Overview of transition for youth with disabilities. *Paediatrician*, 18, 101-104
- Blum RW** (1988) Introduction to health futures of youth. *Journal of Adolescent Health Care*, 9, 1-2S
- Blum RW, Hodgman CH, Jorissen TW, Okinow NA, Orr D & Slap GB** (1993) Transition from child-centered to adult-centered health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 14, 570- 576
- Blum RW, Kelly A & Ireland M** (2001) Health-risk behaviors and protective factors among adolescents with mobility impairments and learning and emotional disabilities. *Journal of Adolescent Health*, 28, 481-490
- Blum RW & Okinow NA** (1993) Teenagers at risk - A national perspective of state level services for adolescents with chronic illness of disability: Executive summary. *Connections: The Newsletter of the National Center for Youth with Disabilities*, 3 (3 SUPPL.), 1-8 July
- Blum RW, Resnick MD, Nelson R, et al** (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88, 280-285
- Blum R & Smith M** (1988) Training of health professionals in adolescent health care: Study group report. *J Adolesc Health Care*, 9, 46-50S
- Blum R, White PH & Gallay L** (2005). Moving into adulthood for youth with disabilities and serious health concerns. *Network on Transitions to Adulthood Policy Brief*, 26. Philadelphia, PA: University of Pennsylvania, MacArthur Research Network on Transitions to Adulthood and Public Policy.
<http://www.transad.pop.upenn.edu/downloads/blum%20disabilities%20final.pdf>
- Bodenheimer T, Lorig K, Holman H & Grumbach K** (2003) Patient self-management of chronic disease in primary care. *JAMA*, 288(19), 2469-2475

- Bolte S & Zebrack B** (2008) Sexual issues in special populations: Adolescents and young adults. *Semin Oncol Nursing*, 24(2), 115-9
- Bolton-Maggs PHB** (2007) Transition of care from paediatric to adult services in haematology. *Archives of Disease in Childhood*, 92 (9), 797-801
- Boslaugh SE & Andresen EM** (2006) Correlates of physical activity for adults with disability. *Prev Chronic Dis*, 3(3), A78
- Bottos M, Feliciangeli A, Sciuto L, Gericke C & Vianello A** (2001) Functional status of adults with cerebral palsy and implications for treatment for children. *Developmental Medicine and Child Neurology*, 43, 516-528
- Bowen M** (2007) Complex palliative care and transition: A case review. *Paediatr Nursing*, 19(9), 42-5
- Bowes G, Sinnema G, Suris J & Buhlmann U** (1995) Transition health services for youth with disabilities: A global perspective. *Conference Proceedings. Journal of Adolescent Health*, 17 (1), 23-31
- Boyd HH & Swedeen B** (2007) A person-centered, asset-based community development framework for youth with special health care needs/disabilities in transition to adulthood. *Journal of Youth Development*, 2 (1). http://www.nae4ha.org/directory/jyd/jyd_article.aspx?id=910b6771-4848-45a9-a7f1-6b414c1d1443
- Boydell KM, Stasiulis E, Greenberg M, Greenberg C & Spiegler B** (2008) I'll show them: The social construction of (in)competence in survivors of childhood brain tumors. *J Pediatr Oncol Nursing*, 25(3), 164-74
- Boyle MP, Farukhi Z & Nosky ML** (2001) Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatric Pulmonol*, 32 (Dec 6), 428-36
- Braj B, Picone G, Children HF, Cross N & Pearlman L** (1999) The lived experience of adolescents who transfer from a pediatric to an adult hemodialysis centre. *CANNT J*, 9 (4), 41-6
- Bray SR & Kwan MY** (2006) Physical activity is associated with better health and psychological well-being during transition to university life. *J Am Coll Health*, 55(2), 77-82
- Britto MT, DeVellis RF, Hornung RW, DeFries GH, Atherton HD & Slap GB** (2004) Health care preferences and priorities of adolescents with chronic illnesses. *Pediatrics*, 114, 1272-80
- Britto MT, Garrett JM, Dugliss MAJ, Johnson CA, Majure JM & Leigh MW** (1999) Preventive services received by adolescents with cystic fibrosis and sickle cell disease. *Archives of Pediatric and Adolescent Medicine*, 153, 27-32
- Britto M, Garrett J & Dugliss M** (1998) Risky behavior in teens with cystic fibrosis or sickle cell disease: A multi-center study. *Pediatrics*, 101, 250-256
- Brodin J & Fasth A** (2001) Habilitation, support and services for young people with motor disabilities: A Swedish perspective. *International Journal of Rehabilitation Research*, 24(4), 309-316
- Brollier C, Sheperd J & Markley KF** (1994) Transition from school to community living. *American Journal of Occupational Therapy*, 48, 346-353
- Bronheim S, Fiel S, Schidlow D, Magrab P, Boczar K & Dillon C** (1990) *Crossings: A Manual for Transition of Chronically Ill Youth to Adult Health Care*. Washington, DC: Georgetown University Child Development Center
- Brookins GK** (1993) Culture, ethnicity, and bicultural competence: Implications for children with chronic illness and disability. *Pediatrics*, 91 (5), 1056-1062
- Brooks F, Bunn F & Morgan J** (2009) Transition for adolescents with long-term conditions: Event to process. *Br J Community Nurs*, 14(7), 301-4
- Brotherson M, Berdine W, & Sartini V** (1993) Transition to adult services: Support for ongoing parent participation. *Remedial and Special Education*, 14(4), 44-51
- Brotherson MJ, Houghton J, Turnbull AP, Bronicki GJ, Roeder-Gordon C, Summers J A, et al** (1988) Transition into adulthood: Parental planning for sons and daughters with disabilities. *Education and Training in Mental Retardation*, 23(3), 165-174

Brown BV (2008) A federal monitoring system for early adult health. *Journal of Adolescent Health*, 3(3), 277-284

Brown BV, Moore KA & Bzostek S (2004) A statistical portrait of well-being in early adulthood. *Cross Currents*, Issue 2, August 2004, Child Trends Publication # 2004-18. www.childtrendsdatbank.org or <http://www.childtrendsdatbank.org/PDF/Young%20Adults%20Brief.pdf>

Brown DE & Thakur MB (2006) Workforce development for older youth. *New Dir Youth Dev*, 111 (Fall), 91-104, 10-1

Brumfield K & Lansbury G (2004) Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: A qualitative study of young Australian adults. *Disabil Rehabil*, 26(4), 223-34

Bruyere SM (1993) Participating action research: Overview and implications for family members of person with disabilities. *Journal of Vocational Rehabilitation*, 3 (2), 62-68

Bryan T, Stiles N, Burstein K, Ergul C & Chao, P-C (2007) "Am I supposed to understand this stuff?" Youth with special health care needs readiness for transition. *Education and Training in Developmental Disabilities*, 42, 330-338

Bryant R & Walsh T (2009) Transition of the chronically ill youth with hemoglobinopathy to adult health care: An integrative review of the literature. *J Pediatr Health Care*, 23(1), 37-48

Bryden K, Peveler R, Stein A, Neil A, Mayou R & Dunger, D (2001) Clinical and psychological course of diabetes from adolescence to young adulthood: A longitudinal cohort study. *Diabetes Care*, 24, 1536-1540

Bryon M & Madge S (2001) Transition from paediatric to adult care: Psychological principles. *Journal of the Royal Medical Society*, 94 (Supplement 40), 5-7

Buck D, Smith M, Appleton R, Baker GA & Jacoby A (2007) The development and validation of the Epilepsy and Learning Disabilities Quality of Life (ELDQOL) scale. *Epilepsy Behav*, 10(1), 38-43

Bullis M, Morgan T, Benz M, Todis B & Johnson MD (2002) Description and evaluation of the ARIES Project: Achieving rehabilitation, individualized education, and employment success for adolescents with emotional disturbance. *Career Development for Exceptional Individuals*, 25, 41-58

Buran CF, McDaniel AM & Brei TJ (2002) Needs assessment in a spina bifida program: A comparison of the perceptions by adolescents with spina bifida and their parents. *Clinical Nurse Specialist*, 16, 256-262

Buran CF, Sawin KJ, Brei TJ & Fastenau PS (2004) Adolescents with myelomeningocele: Activities, beliefs, expectations, and perceptions. *Developmental Medicine & Child Neurology*, 46(4), 244-252

Burdo-Hartman WA & Patel DR (2008) Medical home and transition planning for children and youth with special health care needs. *Pediatr Clin North Am*, 55(6), 1287-97, vii-iii

Burke ME, Albritton K & Marina N (2007) Challenges in the recruitment of adolescents and young adults to cancer clinical trials. *Cancer*, 110(11), 2385-93

Burke R, Spoerri M, Price A, Cardosi AM & Flanagan P (2008) Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. *Clinical Pediatrics (Phila)*, 47(4), 347-54

Burlew K, Telfair J, Colangelo L, & Wright EC (2000) Factors that influence adolescent adaptation to sickle cell disease. *J Pediatr Psychol*, 25, 287-299

Burns JJ, Sadof M & Kamat D (2006) The adolescent with a chronic illness. *Pediatr Ann*, 35(3), 206-10, 214-16

Burstein K, Bryan T, Chao PC, Berger K & Hirsch D (2005) Communication patterns of primary care pediatricians, parents, and children with and without special health care needs. *Journal of Developmental and Physical Disabilities*, 17 (3), 249-262

Burstein K, Bryan T & Chao P (2005) Promoting self-determination skills among youth with special health needs using participatory action research. *Journal of Developmental and Physical Disabilities*, 17 (2), 185-201

Busse FP, Hiermann P, Galler A, Stumvoll M, Wiessner T, Kiess W & Kapellen TM (2007) Evaluation of patients' opinion and metabolic control after transfer of young adults with type 1 diabetes from a pediatric diabetes clinic to adult care. *Horm Res.*, 67(3), 132-8

Cabana MD & Jee SH (2004) Does continuity of care improve patient outcomes? *Journal of Family Practice*, 53, 974-980

- Cadario F, Prodam F, Bellone S, Trada M, Binotti M, Trada M, Allochis G, Baldelli R, Esposito S, Bona G & Aimaretti G** (2009) Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: A hospital-based approach. *Clin Endocrinol (Oxf)*, 71(3), 346-50
- Callahan ST & Cooper WO** (2007) Continuity of health insurance coverage among young adults with disabilities. *Pediatrics*, 119(6), 1175-80
- Callahan ST & Cooper WO** (2006) Access to health care for young adults with disabling chronic conditions. *Archives of Pediatrics & Adolescent Medicine*, 160, 178-182
- Callahan ST & Cooper WO** (2005) Uninsurance and health care access among young adults in the United States. *Pediatrics*, 116, 88-95
- Callahan ST & Cooper WO** (2004) Gender and uninsurance among young adults in the United States. *Pediatrics*, 113, 291-297
- Callahan ST, Winitzer RF & Keenan P** (2001) Transition from pediatric to adult-oriented health care: A challenge for patients with chronic disease. *Current Opinion in Pediatrics*, 13, 310-316
- Cameron CL, Birnie K, Dharma-Wardene MW, Raivio E & Marriott B** (2007) Hospital-to-community transitions. A bridge program for adolescent mental health patients. *J Psychosoc Nurs Ment Health Serv*, 45(10), 24-30
- Cameron JS** (2001) The continued care of children with renal disease into adult life. *Pediatric Nephrology*, 16, 680-685
- Cameron, JS** (1985) The continued care of pediatric patients with renal disease into adult life. *American Journal of Kidney Disease*, 6(2), 91-95
- Cameto R, Levine P & Wagner M** (2004) Transition planning for students with disabilities: A special topic report of findings from the national longitudinal transition study-2 (NLTS2) National Center for Special Education Research. 400 Maryland Avenue SW, Washington, DC
- Canobbio MM** (2001) Health care issues facing adolescents with congenital heart disease. *Journal of Pediatric Nursing*, 16, 363-370
- Cappelli M, MacDonald N & McGrath P** (1989) Assessment of readiness to transfer to adult care for adolescents with cystic fibrosis. *Children's Health Care*, 18 (4), 218-224
- Cardenas DD, Topolski TD, White CJ, McLaughlin JF & Walker WO** (2008) Sexual functioning in adolescents and young adults with spina bifida. *Arch Phys Med Rehabilitation*, 89(1), 31-5
- Carr EG, Horner RH, Turnbull AP, et al** (1999) Positive behavior support for people with developmental disabilities: A research synthesis. Washington DC: American Association on Mental Retardation
- Carroll G, Massarelli E & Otzoomer A** (1983) Adolescents with chronic disease: Are they receiving comprehensive health care? *Journal of Adolescent Health Care*, 4, 261-265
- Carson AR & Hieber KV** (2001) Adult pediatric patients. *American Journal of Nursing*, 101(3), 46 –54
- Carson AR, Hieber KV, Tsamasiros J, Bartsocas CS, McGill M** (2001) Adult pediatric patients—transition of the adolescent from the children's to the adults' diabetes clinic—how do we organize smooth, effective transfer from paediatric to adult diabetes care? *American Journal of Nursing*, 101, 46-55
- Carter EW, Lane KL, Pierson MR & Glaeser B** (2006) Self-determination skills and opportunities of transition-age youth with emotional disturbance and learning disabilities. *Exceptional Children*, 72(3), 333-346
- Carter EW & Wehby JH** (2003) Job performance of transition-age youth with emotional and behavioral disorders. *Exceptional Children*, 69, 449-465
- Casale-Giannola D & Kamens MW** (2006) Inclusion at a university: Experiences of a young woman with Down syndrome. *Ment Retard*, 44(5), 344-52
- Castellino S & Hudson MM** (2002) Health issues in survivors of childhood cancer. *Southern Medical Journal*, 95, 977-984

- Cathels BA & Reddihough DS** (1993) The health care of young adults with cerebral palsy. *Med J Aust*, 159, 444-446
- Caton S & Kagan C** (2007) Comparing transition expectations of young people with moderate learning disabilities with other vulnerable youth and with their non-disabled counterparts. *Disability & Society*, 22(5), 473-488
- Caton S & Kagan C** (2006) Tracking post-school destinations of young people with mild intellectual disabilities: The problem of attrition. *Journal of Applied Research in Intellectual Disabilities*, 19(2), 143-152
- Chambers CR, Hughes C & Carter EW** (2004) Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities*, 39(2), 79-94
- Chaloupka FJ & Johnston LD** (2007) Bridging the gap. Research informing practice and policy for healthy youth behavior. *American Journal of Preventive Medicine*, 33 (4 Suppl), S147-S161
- Chamberlain MA, & Kent RM** (2005) The needs of young people with disabilities in transition from paediatric to adult services. *Eura Medicophys*, 41(2), 111-23
- Chamberlain MA & Rooney CM** (1996) Young adults with arthritis: Meeting their transitional needs. *British Journal of Rheumatology*, 35, 84-90
- Chandler J, O'Brien P & Weinstein L** (1996) The role of occupational therapy in transition from school to work for adolescents with disabilities. *Work*, 6, 53-59
- Chaturvedi S, Jones CL, Walker RG & Sawyer SM** (2009) The transition of kidney transplant recipients: A work in progress. *Pediatr Nephrol*, 24(5), 1055-60
- Chen CM, Chen YC & Haase JE** (2007) Games of lives in surviving childhood brain tumors. *Western Journal of Nursing Research*, 30(4), 435-57
- Chen H, Cohen P, Kasen S, et al.** (2006) Adolescent axis I and personality disorders predict quality of life during young adulthood. *Journal of Adolescent Health*, 39(1), 14-9
- Chen H, Cohen P, Johnson JG, Kasen S & Sneed JR** (2004) Adolescent personality disorders and conflict with romantic partners during the transition to adulthood. *Journal of Personality Disorders*, 18(6), 507-25
- Cheng M & Udry J** (2005) Sexual experiences of adolescents with low cognitive abilities in the US. *Journal of Developmental & Physical Disabilities*, 17(2), 155-172
- Chernausek SD** (2001) Managing the transition of adolescents with GH deficiency. *J Endocrinol Invest*, 24 (Oct 9), 676-80
- Child JS, Collins-Nakai RL & Alpert, JS** (2001) Bethesda Conference Report-Task Force 3: Workforce description and education requirements for the care of adults with congenital heart disease. *J Am Coll Cardiol*, 37, 1183-1187
- Christian BJ & D'Auria JP** (1997) The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing*, 12, 3-12
- Ciclitira PJ & Moodie SJ** (2003) Transition of care between paediatric and adult gastroenterology. Coeliac disease. *Best Prac Res Clin Gastroenterol*, 17(2), 181-95
- Clancy CM & Andresen EM** (2002) Meeting the health care needs of persons with disabilities. *The Milbank Quarterly*, 80 (2), 381-391
- Clarizia NA, Chahal N, Manhiot C, Kilburn J, Redington AN & McCrindle BW** (2009) Transition to adult health care for adolescents and young adults with congenital heart disease: Perspectives of the patient, parent and health care provider. *Can J Cardiol*, 25(9), e317-22
- Clark GM & Kolstoe OP** (1995) *Career development & transition education for adolescents with disabilities*. Boston: Allyn and Bacon
- Clark HB & Davis M, (Eds.)** (2000) *Transition to adulthood: A resource for assisting young people with emotional or behavioral difficulties*. Baltimore: Paul H. Brookes Publishing
- Clark HB, Koroloff N, Geller J & Sondheimer DL** (2008) Research on transition to adulthood: Building the evidence base to inform services and supports for youth and young adults with serious mental health disorders. *J Behav Health Serv Res*, 35(4), 365-72

Clark HB, Pschorr O, Wells P, Curtis M & Tighe T (2004) Transition into community roles for young people with emotional/behavioral difficulties: Collaborative systems and program outcomes. In D. Cheney (Ed.), *Transition issues and strategies for youth and young adults with emotional and/or behavioral difficulties to facilitate movement in to community life.* (pp. 201–226). Arlington, VA: The Council for Children With Behavioral Disorders and the Division of Career Development and Transition, Divisions of the Council For Exceptional Children.

Clark HB, Unger K & Stewart E (1993) Transition of youth and young adults with emotional/behavioral disorders into employment, education and independent living. *Community Alternatives: International Journal of Family Care*, 5, 21-46

Clark HB & Unruth DK (2009) *Transition of youth and young adults with emotional or behavioral difficulties: An evidence-supported handbook.* Baltimore: Paul H Brookes Publishing

Clayton PE, Cuneo RC, Juul A, Monson JP, Shale SM & Tauber M (2005) Consensus statement on the management of the GH-treated adolescent in the transition to adult care. *European Journal of Endocrinology*, 152(2), 165-70

Clayton PE & Shalet SM (2005) Difficulties in patient management associated with the transition period. *Horm Res*, 64 Suppl 2, 74-5

Clegg J, Sheard C, Cahill J & Osbeck L (2001) Severe intellectual disability and transition to adulthood. *British Journal of Medical Psychology*, 74(2), 151-166

Cohen P (2003) Variations in patterns of developmental transitions in the emerging adulthood period. *Developmental Psychology*, 39 (4), 657-669

Cohen P, Chen H, Kasen S, Johnson JG, Crawford T & Gordon K (2005) Adolescent Cluster A personality disorder symptoms, role assumption in the transition to adulthood, and resolution or persistence of symptoms. *Dev Psychopathol*, 17(2), 549-68

Coleman EA & Berenson RA (2004) Lost in transition: Challenges and opportunities for improving the quality of transitional care. *Ann Intern Med*, 141, 533-5

Connelly CE (1987) Self-care and the chronically ill patient. *Nursing Clinics of North America*, 22(3), 621-629

Connolly BH (2001). Aging in individuals with lifelong disabilities. *Physical and Occupational Therapy in Pediatrics*, 21(4), 23-47

Connolly BH (2001) Transition from childhood to adulthood. *Physical and Occupational Therapy in Pediatrics*, 21(4), 1-2

Conti-Ramsden G, Botting N & Durkin K (2008) Parental perspectives during the transition to adulthood of adolescents with a history of specific language impairment (SLI). *J Speech Lang Hear Res*, 51(1), 84-96

Conway GS (2007) Congenital adrenal hyperplasia: Adolescence and transition. *Horm Res*, 68 Suppl 5, 155-157

Conway SP (1998) Transition from paediatric to adult-oriented care for adolescents with cystic fibrosis. *Disabilities and Rehabilitation*, 20, 209-216

Cooke E (2007) Transitional care for young people with diabetes: Policy and practice. *Paediatric Nursing*, 19 (6), 19-22

Cooley WC (2004) Redefining primary pediatric care for children with special health care needs: The primary care medical home. *Current Opinion in Pediatrics*, 16 (6), 689-692

Cooley WC & McAllister J (2004) Building medical homes: Improvement strategies in primary care for CSHCN. *Pediatrics*, 113, 1499-1506

Cooley WC, McAllister J & Sherrieb K (2003) The Medical Home Index: Development and validation of a new practice-level measure of implementation of the Medical Home model. *Ambulatory Pediatrics*, 3, 173-180

Cooney BF (2002) Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Ment Retard*, 40(6), 425-35

Corey AL, Haase JE, Azzouz F & Monahan PO (2008) Social support and symptom distress in adolescents/young adults with cancer. *J Pediatr Oncol Nursing*, 25(5), 275-84

Couriel J (2003) Asthma in adolescence. *Paediatr Respir Rev*, 4(1), 47-54

- Court JM** (1993) Issues of transition to adult care. *Journal of Paediatrics and Child Health*, 29 (1, Supplement), S53-S55
- Court JM** (1991) Outpatient-based transition services for youth. *Pediatrician*, 18,150-6
- Cowlard J** (2003) Cystic fibrosis: Transition from paediatric to adult care. *Nursing Standard*, 18(4), 39-41
- Craig SL, Towns S & Bibby H** (2007) Moving on from paediatric to adult health care: An initial evaluation of a transition program for young people with cystic fibrosis. *Int J Adolesc Med Health*, 19(3), 333-43
- Coyle MK & Martin EM** (2007) Reflecting on a self-care process in the home setting for traumatic brain injury survivors. *J Neurosci Nursing*, 39(5), 274-7
- Crall JJ** (2007) Improving oral health for individuals with special health care needs. *Pediatr Dent*, 29(2), 98-104
- Crittenden PM** (1990) Toward a concept of autonomy in adolescents with a disability. *Children's Health Care*, 19(3), 162-168
- Cromer BA, Enrile B & McCoy K** (1989) Knowledge, attitudes and behavior related to sexuality in adolescents with chronic disability. *Developmental Medicine Childhood Neurology*, 32, 602-610
- Cuttell K, Hilton D & Drew J** (2005) Preparation for transition to adult diabetes services. *Paediatric Nursing*, 17(2), 28-30.
- Cystic Fibrosis Foundation Center Committee and Guidelines Subcommittee** (1990) Cystic Fibrosis Foundation guidelines for patient services, evaluation, and monitoring in cystic fibrosis centers. *Am J Dis Child*, 144, 1311-1312
- Dabadie A, Troadec F, Heresbach D, Siproudhis L, Pagenault M & Bretagne JF** (2008) Transition of patients with inflammatory bowel disease from pediatric to adult care. *Gastroenterol Clin Biol*, 32(5 Pt 1), 451-9
- Damiano PC, Momany ET, Tyler MC, Penziner, AJ & Lobas JG** (2006) Cost of outpatient medical care for children and youth with special health care needs: Investigating the impact of the medical home. *Pediatrics*, 118(4), e1187-e1194
- David TJ** (2001) Transition from paediatric clinic to the adult service. *Journal of the Royal Society of Medicine*, 94, 373-374
- Davies IH & Jenkins HR** (2003) Transition clinics for adolescents with chronic gastrointestinal disease in the UK and Ireland. *J Pediatr Gastroenterol Nutr*, 36(4), 505-6
- Davies PS & Rupp K** (2005-2006) An overview of the National Survey of SSI Children and Families and related products, 66(2), 7-20
- Davis M** (2003) Addressing the needs of youth in transition to adulthood. *Adm Policy Mental Health*, 30 (6), 495-509
- Davis M, Banks S, Fisher W & Grudzinskas A** (2004) Longitudinal patterns of offending during the transition to adulthood in youth from the mental health system. *Journal of Behavioral Health Services Research*, 31(4), 351-66
- Davis M, Geller JL & Hunt B** (2006) Within-state availability of transition-to-adulthood services for youths with serious mental health conditions. *Psychiatr Serv*, 57(11), 1594-9
- Davis M & Sondheimer DL** (2005) State child mental health efforts to support youth in transition to adulthood. *Journal of Behavioral Health Services Research*, 32(1), 27-42
- Davis M & Vander Stoep A** (1997) The transition to adulthood among children and adolescents who have serious emotional disturbance, Part I: Developmental transitions. *Journal of Mental Health Administration*, 24, 400-427
- Day SM, Wu YW, Strauss DJ, Shavelle RM & Reynolds RJ** (2007) Change in ambulatory ability of adolescents and young adults with cerebral palsy. *Dev Med Child Neurol*, 49(9), 647-53
- Deanfield JE & Celermajer DS** (1991) Adults with congenital heart disease. A comprehensive service is needed. *BMJ*, 303, 1413-1414

DeJong G, Palso GE & Beatty PW (2002) The organization and financing of health services for persons with disabilities. *The Milbank Quarterly*, 80 (2), 261-301

Dennis RE, Williams W, Giangreco MF & Cloninger CJ (1993) Quality of life as context for planning and evaluation of services for people with disabilities. *Exceptional Children*, 59(6), 499-512

DePoy E & MacDuffie H (2004) Force field analysis: A model for promoting adolescent involvement in their own health care. *Journal of Health Promotion Practice*, 5(3), 306-313

DePoy E, Gilmer D & Martzial E (2000) Adolescents with disabilities and chronic illness in transition: A community action needs assessment. *Disability Studies Quarterly*, 20 (1), 16-24

DePoy E, Hartman A, Francis C & Gilmer D (2000) The life histories of adolescents with special health care needs in transition as told by their parents: A qualitative study. *Social Work & Health Care*, 31 (4), 3-58

Devernay M, Ecosse E, Coste J & Carel JC (2009) Determinants of medical care for young women with Turner syndrome. *J Clin Endocrinol Metab*, 94(9), 3408-13

Dick M-L (2003) Chronic illness in young Australian adults. *Medical Journal of Australia*, 179(5), 238

DiNapoli PP & Murphy D (2002) The marginalization of chronically ill adolescents. *Nursing Clinics North America*, 37(3), 565-72

Dobson JV, Bryce L, Glaeser PW & Losek JD (2007) Age limits and transition of health care in pediatric emergency medicine. *Pediatr Emerg Care*, 23(5), 294-7

Dodds S, Blakley T, Lizzotte JM, Friedman LB, Shaw K, Martinez J, Siciliano C, Walker LE, Sotheran JL, Sell RL, Botwinick G, Johnson RL & Bell D (2003) Retention, adherence, and compliance: Special needs of HIV-infected adolescent girls and young women. *Journal of Adolescent Health*, 33 (2 SUPPL. 2), 39-45

Donkervoort M, Roebroek M, Wiegerink D, van der Heijden-Maessen H & Stam H (2007) Determinants of functioning of adolescents and young adults with cerebral palsy. *Disabil Rehabil*, 29(6), 453-63

Donkervoort M, Wiegerink DJ, van Meeteren J, Stam HJ & Roebroek ME (2009) Transition to adulthood: Validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Dev Med Child Neurol*, 51(1), 53-62

Donnelly C, Parkes J, McDowell B & Duffy C (2008) Lifestyle limitations of children and young people with severe cerebral palsy: A population study protocol. *Journal of Advanced Nursing*, 61(5), 557-69

Dore A, de Guise P & Mercier LA (2002) Transition of care to adult congenital heart centres: What do patients know about their heart condition? *Can J Cardiol*, 18(2), 141-6

Dougall A & Fiske J (2008) Access to special care dentistry, part 6. Special care dentistry services for young people. *Br Dent J*, 205(5), 235-49

Douglas N & Plugge E (2008) The health needs of imprisoned female juvenile offenders: The views of the young women prisoners and youth justice professionals. *Int J Prison Health*, 4(2), 66-76

Dovey-Pearce G, Hurrell R, May C, Walker C & Doherty Y (2005) Young adults' (16-25 years) suggestions for providing developmentally appropriate diabetes services: A qualitative study. *Health Soc Care Community*, 13(5), 409-19

Downes JJ & Boroughs DS (2005) The transition to adulthood by adolescents with chronic respiratory failure: A growing challenge. *Caring*, 24(9), 62-7

Doyle M, Siegel R & Supe K (2007) Stages of change and transitioning for adolescent patients with obesity and hypertension. *Adv Chronic Kidney Dis*, 13(4), 386-93; erratum in: *Adv Chronic Kidney Dis*, 14(1), 112

Drew S (2007) 'Having cancer changed my life, and changed my life forever': Survival, illness legacy and service provision following cancer in childhood. *Chronic Illn*, 3(4), 278-95

Drotar D (1997) Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology*, 22(2), 149-165

Duffey-Lind EC, O'Holleran E, Healey M, Vettese M, Diller L & Park ER (2006) Transitioning to survivorship: A pilot study. *J Pediatr Oncol Nursing*, 23(6), 335-43

Duguépéroux I, Tamalet A, Sermet-Gaudelus I, Le Bourgeois M, Gérardin M, Desmazes-Dufeu N & Hubert D (2008) Clinical changes of patients with cystic fibrosis during transition from pediatric to adult care. *Journal of Adolescent Health*, 43(5), 459-465

Dunn C (1996) A status report transition planning for individuals with learning disabilities. *Journal of Learning Disabilities*, 29, 17-30

Edelstein BL (2007) Conceptual frameworks for understanding system capacity in the care of people with special health care needs. *Pediatr Dent*, 29(2), 108-116

Eiser C, Absolom K, Greenfield D, Snowden J, Coleman R, Hancock B & Davies H (2007) Follow-up care for young adult survivors of cancer: Lessons from pediatrics. *J Cancer Surviv*, 1(1), 75-86

Eiser C, Flynn M, Green E, Havermans T, Kirby R, Sandeman D & Tooke JE (1993) Coming of age with diabetes: Patients' views of a clinic for under-25 year olds. *Diabetic Medicine*, 10, 285-289

Ellingford C (2006) Short report: Refocusing transition clinics. *Paediatric Nursing*, 18(6), 37

EI-Matary W (2009) Transition of children with inflammatory bowel disease: Big task, little evidence. *World J Gastroenterol*, 15(30), 3744-7

Elster AB & Levenberg P (1997) Integrating comprehensive adolescent preventive services into medicine care. *Pediatric Clinics of North America*, 44, 1365-1377

Endermann M & Zimmermann F (2009) Factors associated with health-related quality of life, anxiety and depression among young adults with epilepsy and mild cognitive impairments in short-term residential care. *Seizure: European Journal of Epilepsy*, 18 (3), 167-175

Enns GM & Packman W (2002) The adolescent with an inborn error of metabolism: Medical issues and transition to adulthood. *Adolescent Medicine*, 13(2), 315-29, vii

Enskär K & von Essen L (2007) Prevalence of aspects of distress, coping, support and care among adolescents and young adults undergoing and being off cancer treatment. *Eur J Oncol Nursing*, 11(5), 400-8

Escher JC (2009) Transition from pediatric to adult health care in inflammatory bowel disease. *Dig Dis*, 27(3), 382-6

Evan EE, Kaufman M, Cook AB & Zeltzer LK (2006) Sexual health and self-esteem in adolescents and young adults with cancer. *Cancer*, 107(S7), 1672-1679

Evans J, McDougall J & Baldwin P (2006) An evaluation of the "Youth en Route" program. *Phys Occup Ther Pediatr*, 26(4), 63-87

Evans PM, Evans SJ & Alberman E (1990) Cerebral palsy: Why we must plan for survival. *Arch Dis Child*, 65, 1329-33

Evans RL, Connis RT, & Haselkorn JK (1998) Hospital-based rehabilitative care versus outpatient services: Effect on functioning and health status. *Disability & Rehabilitation*, 20(8), 298-307

Evans RL, Dingus CM, & Haselkorn JK (1993) Living with a disability: A synthesis and critique of the literature on quality of life, 1985-1989. *Psychological Reports*, 72(3 Pt 1), 771-777

Evers RB (1996) The positive force of vocational education: Transition outcomes for youth with learning disabilities. *Journal of Learning Disabilities*, 27, 51-59

Everson J & Moon M (1987) Transition services for young adults with severe disabilities: Defining professional and parental roles and responsibilities. *JASH*, 12(2), 87-95

Everson JM, Zhang D & Guillory JD (2001) A statewide investigation of individualized transition plans in Louisiana. *Career Development for Exceptional Individuals*, 24, 37-49

Fabian ES (2007) Urban youth with disabilities: Factors affecting transition employment. *Rehabilitation Counseling Bulletin*, 50(3), 130-138

- Fair A, Griffiths K & Osman LM** (2000) Attitudes to fertility issues among adults with cystic fibrosis in Scotland: The collaborative group of Scottish adult cystic fibrosis centres. *Thorax*, 55(8), 672-7
- Falcini F & Nacci F** (2007) Systemic lupus erythematosus in the young: The importance of a transition clinic. *Lupus*, 16 (8), 613-617
- Fallon S, Smith J, Morgan S, Stoner M & Austin C** (2008) 'Pizza, patients and points of view': Involving young people in the design of a post registration module entitled the adolescent with cancer. *Nurse Educ Pract*, 8(2), 140-7
- Farrant B & Watson PD** (2004) Health care delivery: Perspectives of young people with chronic illness and their parents. *J Paediatr Child Health*, 40, 175-9
- Feldman BJ, Conger RD & Burzette RG** (2004) Traumatic events, psychiatric disorders, and pathways of risk and resilience during the transition to adulthood. *Research in Human Development*, 1(4), 259-290
- Ferguson PM, Ferguson DL & Jones D** (1988) Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. *Journal of the Association for Persons with Severe Handicaps*, 13(3), 177-187
- Ferris ME & Mahan JD** (2009) Pediatric chronic kidney disease and the process of health care transition. *Semin Nephrol*, 29(4), 435-44
- Fielden SJ, Shekter L, Chapman GE, Alimenti A, Forbes JC, Sheps S, Cadell S & Frankish JC** (2006) Growing up: Perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. *AIDS Care*, 18(8), 1050-3
- Fine M & McClelland S** (2006) Sexuality education and desire: Still missing after all these years. *Harvard Educational Review*, 76(3), 297-338
- Florentino L, Datta D, Gentle S, Hall DM, Harpin V, Phillips D & Walker A** (1998) Transition from school to adult life for physically disabled young people. *Archives of Disabled Children*, 79, 306-311
- Florentino L, Philips D, Walker A & Hall D** (1998) Leaving paediatrics: The experience of service transition for young disabled people and their family carers. *Health and Social Care in the Community*, 6(4), 260-270
- Fishman E** (2001) Aging out of coverage: Young adults with special health needs. *Health Affairs*, 20 (6), 254-266
- Fleming E, Carter B & Gillibrand W** (2002) The transition of adolescents with diabetes from the children's health care service into the adult health care service: A review of the literature. *Journal of Clinical Nursing*, 11 (5), 560-7
- Fleming M** (2004) On transition to young adulthood: A prospective study. *Int J Psychoanal*, 85(Pt 2), 527-8
- Flume PA, Anderson DL, Hardy KR & Gray S** (2001) Transition programs in cystic fibrosis centers: Perceptions of pediatric and adult program directors. *Pediatric Pulmonology*, 31, 443-450
- Flume PA, Taylor LA, Anderson DL, Gray S & Turner D** (2004) Transition programs in cystic fibrosis centers: Perceptions of team members. *Pediatric Pulmonology*, 37(1), 1-3
- Forbes A, While A, Ullman R, Lewis S, Mathes L & Griffiths P** (2001) A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)
- Ford CA, Bearman PS & Moody J** (1999) Foregone health care among adolescents. *The Journal of the American Medical Association*, 282 (23), 2227-2234
- Foster L & Holmes Y** (2007) Transition from paediatric to adult service in epidermolysis bullosa. *British Journal of Nursing*, 16(4), 244-6
- Fox A** (2002) Physicians as barriers to successful transitional care. *Int J Adolesc Med Health*, 14(1), 3-7
- Fox KC, Somes GW & Waters TM** (2007) Timeliness and access to healthcare services via telemedicine for adolescents in state correctional facilities. *J Adolesc Health*, 41(2), 161-7

- Fox MH & Kim KM** (2004) Evaluating a Medicaid home and community-based physical disability waiver. *Family and Community Health*, 27(1), 37-51
- Francis D** (1995) Bridging the gaps: Adolescents with clotting disorders transition to adult care. *Nursing Network/Psychosocial News*, (Summer), 10-11
- Frank A & Sitlington P** (1993) Graduates with mental disabilities: The story three years later. *Education and Training in Mental Retardation*, 28(1), 30-37
- Freeman HS & Newland LA** (2002) Family transitions during the adolescent transition: Implications for parenting. *Adolescence*, 37 (147), 457-75
- Freyer DR & Brugieres L** (2008) Adolescent and young adult oncology: Transition of care. *Pediatr Blood Cancer*, 50(5 Suppl), 1116-9
- Freyer DR & Kibrick-Lazear R** (2006) In sickness and in health: Transition of cancer-related care for older adolescents and young adults. *Cancer*, 107(S7), 1702-1709
- Friedman D, Holmbeck GN, Jandasek B, Zukerman J & Abad M** (2004) Parent functioning in families of preadolescents with spina bifida: Longitudinal implications for child adjustment. *Journal of Family Psychology*, 18(4), 609-19
- Fulginiti VA** (1992) What is pediatrics? Perinatal medicine to young adult care. *Am J Disabled Children*, 146, 17-18
- Furney KS, Hasazi SB & Destefano L** (1997) Transition policies, practices, and promises: Lessons from three states. *Exceptional Children*, 63(3), 343-355
- Future of Family Medicine Project Leadership Committee** (2004) The future of family medicine: A collaborative project of the family medicine community. *Annals of Family Medicine*, 2 (Suppl 1):S3-S32
- Gaebler-Spira D & Thornton LS** (2002) Injury prevention for children with disabilities. *Physical Medicine Rehabilitation Clinics of North America*, 13(4), 891-906
- Gajdosik CG & Cicirello N** (2001) Secondary conditions of the musculoskeletal system in adolescents and adults with cerebral palsy. *Phys Occup Ther Pediatr*, 21, 49-68
- Galambos NL, Darrah J & Magill-Evans J** (2007). Subjective age in the transition to adulthood for persons with and without motor disabilities. *Journal of Youth and Adolescence*, 36(6), 825-834
- Gall C, Kingsnorth S & Healy H** (2006) Growing Up Ready: A shared management approach. *Physical and Occupational Therapy in Pediatrics*, 26(4), 47 - 62
- Gallivan-Fenlon A** (1994) "Their senior year": Family and service provider perspectives on the transition from school to adult life for young adults with disabilities. *Journal of the Association for Persons with Severe Handicaps*, 9(1), 11-23
- Gans BM, Mann NR & Becker BE** (1993) Delivery of primary care to the physically challenged. *Arch Phys Med Rehabil*, 74 (Suppl), S15-9
- Garwick A, Kohrman C, Wolman C & Blum R** (1998) Families' recommendations for improving services for children with chronic conditions. *Archives of Pediatrics and Adolescent Medicine*, 152 (5), 440-448
- Gee L, Smith TL, Solomon M, Quinn MT & Lipton RB** (2007) The clinical, psychosocial, and socioeconomic concerns of urban youth living with diabetes. *Public Health Nursing*, 24(4), 318-28
- Geenen S & Powers LE** (2006) Transition planning for foster youth with disabilities: Are we falling short? *Journal for Vocational Special Needs Education*, 28(2), 4-15
- Geenen S, Powers LE & Lopez-Vasquez A** (2006) Barriers against and strategies for promoting the involvement of culturally diverse parents in school-based transition planning. *Journal of Vocational Special Needs Education*, 27(3), 4-14
- Geenen SJ, Powers LE & Sells W** (2003) Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health*, 32(3), 225-233

- Gerber PJ, Price LA, Mulligan R, & Shessel I** (2004) Beyond transition: A comparison of the employment experiences of American and Canadian adults with LD. *Journal of Learning Disabilities*, 37(4), 283-91
- Gerhardt CA, Dixon M, Miller K, Vannatta K, Valerius KS, Correll J, et al** (2007) Educational and occupational outcomes among survivors of childhood cancer during the transition to emerging adulthood. *Journal of Developmental and Behavioral Pediatrics*, 28(6), 448-455
- Gerhardt CA, McGoron KD, Vannatta K, McNamara KA, Taylor J, Passo M & Noll RB** (2008) Educational and occupational outcomes among young adults with juvenile idiopathic arthritis. *Arthritis Rheum*, 59(10), 1385-91
- Gerhardt CA, Vannatta K, Valerius KS, et al.** (2007) Social and romantic outcomes in emerging adulthood among survivors of childhood cancer. *Journal of Adolescent Health*, 40(5), 462, e9-15
- Giarelli E, Bernhardt BA, Mack R & Pyeritz RE** (2008) Adolescents' transition to self management of a chronic genetic disorder. *Qualitative Health Research*, 18(4), 441-457
- Giedd JN** (2008) The teen brain: Insights from neuroimaging. *Journal of Adolescent Health*, 42(4), 335-343
- Giedd JN** (2004) Structural magnetic resonance imaging of the adolescent brain. *Annals of the New York Academy of Sciences*, 1021 (June), 77-85
- Gill CJ** (1996) Becoming visible: Personal health experiences of women with disabilities. In Krotoski DM, Nosek MA, Turk MA, editors. *Women with physical disabilities: Achieving and maintaining health and well-being*. Baltimore: Paul H. Brookes, 5-15
- Gill CJ, Kirschner KL, & Panko R J** (1994) Health services for women with disabilities: Barriers and portals. In: Dan AJ, editor. *Reframing women's health*. Thousand Oaks, CA: Sage Publications, 357-66
- Gillibrand R & Stevenson J** (2007) The role of partner relationships in the young person's adherence to the diabetes self-care regime. *Int J Behav Med*, 14(3), 151-5
- Gil-Kashiwabara E, Hogansen JM, Geenen S, Powers K & Powers LE** (2007) Improving transition outcomes for marginalized youth. *Career Development for Exceptional Individuals*, 30 (2), 80-91
- Gillman D & Schlicht B** (2005) Transition to adult health care: A training guide in two parts In *Healthy and Ready to Work: A Series of Materials Supporting Youth With Special Health Care Needs*, Waisman Center, University of Wisconsin, University Center for Excellence in Developmental Disabilities, Madison, WI.
<http://www.waisman.wisc.edu/>
- Ginsberg JP, Hobbie WL, Carlson CA & Meadows AT** (2006) Delivering long-term follow-up care to pediatric cancer survivors: Transitional care issues. *Pediatric Blood Cancer*, 46 (2), 169-73
- Glauser TA** (2004) Following catastrophic epilepsy patients from childhood to adulthood. *Epilepsia*, 45 Suppl 5, 23-6
- Glidden LM & Jobe BM** (2007) Measuring parental daily rewards and worries in the transition to adulthood. *Am J Ment Retard*, 112(4), 275-88
- Gogtay N, Giedd JN, Lusk L, Hayashi KM, Greenstein D, Vaituzis AC, Nugent TF 3rd, Herman DH, Clasen LS, Toga AW, Rapoport JL & Thompson PM** (2004) Dynamic mapping of human cortical development during childhood through early adulthood. *Proc Natl Acad Sci U S A*, 101(21), 8174-9
- Gokhale R & Kirschner BS** (2003) Transition of care between paediatric and adult gastroenterology. Assessment of growth and nutrition. *Best Pract Res Clin Gastroenterol*, 17(2), 153-62
- Goldscheider F & Goldscheider C** (1999) *The Changing Transition to Adulthood: Leaving and Returning Home*. Sage Publishing Company
- Goldstein MA** (2002) Preparing adolescent patients for college. *Curr Opin Pediatrics*, 14, 384-8
- Gong GW, Barrera M, Beyene J, Bhat S, Carcao M, Lord S, Narayanan UG, Sung L, Young NL & Feldman BM** (2007) The Gap Study (GapS) interview--developing a process to determine the meaning and determinants of quality of life in children with arthritis and rheumatic disease. *Clin Exp Rheumatol*, 25(3), 486-93
- Goode TC, Dunne MC & Bronheim SM** (2006) The evidence base for cultural and linguistic competency in healthcare. *The Commonwealth Fund*; October. Available at http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=413821

- Goodman DM, Mendez E, Throop C & Ogata ES** (2002) Adult survivors of pediatric illness: The impact on pediatric hospitals. *Pediatrics*, 110(3), 583-589
- Gordon JB, Colby HH, Bartelt T, Jablonski D, Krauthoefer ML & Havens P** (2007) A tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Arch Pediatr Adolesc Med*, 161(10), 937-44
- Gordon-Larsen P, Nelson MC & Popkin BM** (2004) Longitudinal physical activity and sedentary behavior trends: Adolescence to adulthood. *American Journal of Preventive Medicine*, 27(4), 277-83
- Gore S & Aseltine RH Jr** (2003) Race and ethnic differences in depressed mood following the transition from high school. *J Health Soc Behav*, 44(3), 370-89
- Gortmaker SL, Perrin JM & Weitzman M** (1993) An unexpected success story: Transition to adulthood in youth with chronic physical health conditions. *J Res Adolesc*, 3, 317-336
- Gortmaker SL, Walker DK, Weitzman PI & Scbol AM** (1990) Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. *Pediatrics*, 85 (3), 267-276
- Gotlieb EM & Gotlieb JS** (2009) Helping adolescents with attention-deficit/ hyperactivity disorder transition toward adulthood. *Adolesc Med State Art Rev*, 20(1), 203-22, xi
- Goyette M** (2007) Promoting autonomous functioning among youth in care: A program evaluation. *New Directions for Youth Development*, (113), 89-105, 12
- Grabois E** (2001) Guide to getting reproductive health care services for women with disabilities under the Americans with Disabilities Act of 1990. *Sexuality and Disability*, 19(3), 191-208
- Grabois EW, Nosek MA & Rossi CD** (1999) Accessibility of primary care physicians' offices for people with disabilities. An analysis of compliance with the Americans with Disabilities Act. *Archives Family Medicine*, 8 (1), 44-51
- Grace TW** (1998) Health problems of late adolescence. *Primary Care*, 25, 237-252
- Green CW & Reid DH** (1999) A behavioral approach to identifying sources of happiness and unhappiness among individuals with profound multiple disabilities. *Behavior Modification*, 23(2), 280-293
- Greenbaum P, Dedrick R, Friedman R, Kutash K, Brown E, Lardierei S & Pugh, A** (1996) National Adolescent and Child Treatment Study (NACTS): Outcomes for children with serious emotional and behavioral disturbance. *Journal of Emotional and Behavioral Disorders*, 4, 130-146
- Griffiths JA, Morgan K, Barber VS & Young JD** (2008) Study protocol: The Intensive Care Outcome Network ('ICON') study. *BMC Health Serv Res*, 8, 132
- Grinyer A** (2007) The biographical impact of teenage and adolescent cancer. *Chronic Illn*, 3(4), 265-77
- Grinyer A** (2004) Young adults with cancer: Parents' interactions with health care professionals. *Eur J Cancer Care (Engl)*, 13(1), 88-95
- Groce NE & Zola IK** (1993) Multiculturalism, chronic illness, and disability. *Pediatrics*, 91 (5), 1048-1055
- Grootenhuis MA, Stam H, Last BF & Groothoff JW** (2006) The impact of delayed development on the quality of life of adults with end-stage renal disease since childhood. *Pediatr Nephrol*, 21(4), 538-44
- Grover S** (2002) Menstrual and contraceptive management in women with an intellectual disability. *Medical Journal of Australia*, 176, 108-110
- Gurney JG, Donohue JE, Ness KK, O'Leary M, Glasser SP & Baker KS** (2007) Health knowledge about symptoms of heart attack and stroke in adult survivors of childhood acute lymphoblastic leukemia. *Ann Epidemiol*, 17(10), 778-81
- Gurney JG, McPheeters ML & Davis MM** (2006) Parental report of health conditions and health care use among children with and without autism: National Survey of Children's Health. *Archives Pediatric Adolesc Med*, 160(8), 825-30
- Gurvitz MZ, Inkelas M, Lee M, Stout K, Escarce J & Chang RK** (2007) Changes in hospitalization patterns among patients with congenital heart disease during the transition from adolescence to adulthood. *J Am Coll Cardiol*, 49(8), 875-82

- Gutman LM & Sameroff AJ** (2004) Continuities in depression from adolescence to young adulthood: Contrasting ecological influences. *Dev Psychopathol*, 16(4), 967-84
- Gutman SA** (1999) Case report. The transition through adult rites of passage after traumatic brain injury: Preliminary assessment of an occupational therapy intervention. *Occupational Therapy International*, 6(2), 143-158
- Haas SA & Fosse NE** (2008) Health and the educational attainment of adolescents: Evidence from the NLSY97. *J Health Soc Behav*, 49(2), 178-92
- Haber MG, Karpur A, Deschenes N & Clark, HB** (2008) Predicting improvement of transitioning young people in the partnerships for youth transition initiative: Findings from a multisite demonstration. *J Behav Health Serv Res*, 35(4), 488-513
- Hack M** (2006) Young adult outcomes of very-low-birth-weight children. *Semin Fetal Neonatal Med*, 11(2), 127-37
- Hager A & Hess J** (2005) Comparison of health related quality of life with cardiopulmonary exercise testing in adolescents and adults with congenital heart disease. *Heart*, 91 (4), 517-20
- Hagood JS, Lenker CV & Thrasher S** (2005) A course on the transition to adult care of patients with childhood-onset chronic illnesses. *Academic Medicine*, 80(4), 352-5
- Hait E, Arnold JH & Fishman LN** (2006) Educate, communicate, anticipate-practical recommendations for transitioning adolescents with IBD to adult health care. *Inflamm Bowel Dis*, 12(1), 70-3
- Hait EJ, Barendse RM, Arnold JH, Valim C, Sands BE, Korzenik JR & Fishman LN** (2009) Transition of adolescents with inflammatory bowel disease from pediatric to adult care: A survey of adult gastroenterologists. *J Pediatr Gastroenterol Nutr*, 48(1), 61-5
- Hall J & Starrett B** (2007) Assessing the health care needs of Kansas' young adults with disabilities. *Kansas Nurse*, 82(7), 5-7
- Hall JP, Kurth NK & Moore JM** (2007) Transition to Medicare Part D: An early snapshot of barriers experienced by younger dual eligibles with disabilities. *Am J Manag Care*, 13(1), 14-8
- Haller DM, Sancu LA, Patton GC, et al** (2007) Toward youth friendly services: A survey of young people in primary care. *J Gen Intern Med.*, 22(6), 775-81
- Halloran W & Ward M** (1988) Improving transition programming: Changing special education's focus. *The Pointer*, 32, 43-46
- Hallum A** (1995) Disability and the transition to adulthood: Issues for the disabled child, the family, and the pediatrician. *Current Problems in Pediatrics*, (25), 12-50
- Hallum A** (1990) Exploratory study on the impact of parents caring for physically dependent severely disabled adult age children at home. *Disabled Abstracts International*, 51 (2B), 296
- Halpern AS** (1994) The transition of youth with disabilities to adult life: A position statement of the division on career development and transition, the Council for Exceptional Children. *Career Dev. Except Individ*, 17 (2), 115-124
- Halpern AS** (1991) Transition: Old wine in new bottles. *Exceptional Children*, 58(3), 202-210
- Halpern AS** (1985) Transition: A look at the foundations. *Exceptional Children*, 51, 479-486
- Halpern AS & Benz MR** (1987) A statewide examination of secondary special education for students with mild disabilities: Implications for high school curriculum. *Exceptional Children*, 54, 122
- Hanley-Maxwell C, Whitney-Thomas J & Pogoloff SM** (1995) The second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life. *Journal of the Association for Persons with Severe Handicaps*, 20(1), 3-15.
- Harden PN & Nadine P** (2006) Pediatric to adult transition: A personal experience. *Prog Transplant*. 16(4), 324-8
- Hardoff D & Chigier E** (1991) Developing community-based services for youth with disabilities. *Pediatrician*, 18(2), 157-62
- Haring KA & Lovett DL** (1990) A follow-up study of special education graduates. *The Journal of Special Education*, 23(4), 463-477

- Harnisch D & Snauwaert D** (1992) Exiting school: Who cares about youth with disabilities? In D. Harnisch, T. Wermuth & F. Rusch (Eds) *Selected Readings in Transition*. Champaign, IL: Transition Research Institute
- Harris KM, Gordon-Larsen P, Chantala K & Udrey JR** (2006) Longitudinal trends in race/ethnic disparities in leading health indicators from adolescence to young adulthood. *Arch Pediatr Adolesc Med*, 160 (1), 74-81
- Harrison ME, McKay MM & Bannon WM** (2004) Inner-city child mental health service use: The real question is why youth and families do not use services. *Community Ment Health J*, 40(2), 119-31
- Harrison T** (2003) Women aging with childhood onset disability: A holistic approach using the life course paradigm. *Journal of Holistic Nursing*, 21(3), 242-259
- Harrop M** (2007) Psychosocial impact of cystic fibrosis in adolescence. *Paediatric Nursing*, 19(10), 41-5
- Hartman A, DePoy E, Francis C & Gilmer D** (2000) Adolescents with special health care needs in transition: Three life histories. *Social Work & Health Care*, 31 (4), 43-57
- Hartwell SW, Fisher WH & Davis M** (2009) Emerging adults with psychiatric disabilities involved with the criminal justice system. *Int J Offender Ther Comp Criminol*. 2009 Jun 4. [Epub ahead of print]
- Hasazi SB, Gordon LR & Roe GA** (1985) Factors associated with the employment status of handicapped youth exiting high school for 1979 to 1983. *Exceptional Children*, 57, 455-469
- Hatton C, Emerson E, Robertson J, Henderson D & Cooper J** (1995) The quality and costs of residential services for adults with multiple disabilities: A comparative evaluation. *Research in Developmental Disabilities*, 16(6), 439-460
- Hauser E & Dorn L** (1999) Transitioning adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing*, 25(5), 479-488
- Hayden PW, Davenport SL & Campbell MM** (1979) Adolescents with myelodysplasia: Impact of physical disability on emotional maturation. *Pediatrics*, 64, 539
- Healy H & Rigby P** (1999) Promoting independence for teens and young adults with physical disabilities. *Canadian Journal of Occupational Therapy*, 66(5), 240-248
- Heflinger CA & Hoffman C** (2008) Transition age youth in publicly funded systems: Identifying high-risk youth for policy planning and improved service delivery. *Journal of Behavioral Health Services & Research*, 35(4), 390-401
- Heiden J** (1989) A ten-year follow-up study of former students at the Wisconsin School for the Handicapped: 1978-1987. *RE:view*, 21 (2), 81-89
- Helgeson VS, Snyder PR, Escobar O, Siminerio L & Becker D** (2007) Comparison of adolescents with and without diabetes on indices of psychosocial functioning for three years. *J Pediatr Psychol*, 32(7), 794-806
- Hellstedt LF** (2004) Transitional care issues influencing access to health care: Employability and insurability. *Nursing Clinics North America*, 39(4), 741-53
- Hepper F & Garralda ME** (2001) Psychiatric adjustment to leaving school in adolescents with intellectual disability: A pilot study. *J Intellect Disabil Res*, 45(Dec Pt 6), 521-5
- Hergenroeder AC** (2002) The transition into adulthood for children and youth with special health care needs. *Texas Med*, 98(Feb 2), 51-8
- Hern MJ, Beery TA & Barry DG** (2006) Experiences of college-age youths in families with a recessive genetic condition. *Journal of Family Nursing*, 12(2 May), 119-42
- Heslop P & Abbott D** (2007) School's out: Pathways for young people with intellectual disabilities from out-of-area residential schools or colleges. *J Intellect Disabil Res*, 51(Pt 7), 489-96
- Hewer SC & Tyrrell J** (2008) Cystic fibrosis and the transition to adult health services. *Arch Dis Child*, 93(10), 817-21
- Hickie IB, Fogarty AS, Davenport TA, Luscombe GM & Burns J** (2007) Responding to experiences of young people with common mental health problems attending Australian general practice. *Med J Aust*, 187(7 Suppl), S47-52

- Higgins SS & Tong E** (2003) Transitioning adolescents with congenital heart disease into adult health care. *Prog Cardiovasc Nursing*, 18(2), 93-8
- Hilberink SR, Roebroek ME, Nieuwstraten W, Jalink L, Verheijden JM & Stam HJ** (2007) Health issues in young adults with cerebral palsy: Towards a life-span perspective. *J Rehabil Med*, 39(8), 605-11
- Hill AE** (1993) Problems in relations to independent living: A retrospective study of physically disabled school learners. *Developmental Medicine and Child Neurology*, 35, 1111-1115
- Hill K** (2009) Individuals with Disabilities Act of 2004 and the John H. Chafee Foster Care Independence Act of 1999: What are the policy implications for youth with disabilities transitioning from foster care? *Child Welfare*, 88(2), 5-23
- Hines A** (2007) On Your Own Without a Net: The Transition to Adulthood for Vulnerable Populations. Edited by DW Osgood, EM Foster, C Flanagan & GR Ruth, *Journal of Marriage and Family*, 69 (2), 549-551
- Hines AM, Merdinger J & Wyatt P** (2005) Former foster youth attending college: Resilience and the transition to young adulthood. *Am J Orthopsychiatry*, 75 (3), 381-94
- Hobbie WL & Ogle S** (2001) Transitional care for young adult survivors of childhood cancer. *Semin Oncol Nurs*, 17(Nov 4), 268-73
- Hobcraft G & Baker T** (2006) Special needs of adolescent and young women in accessing reproductive health: Promoting partnerships between young people and health care providers. *International Journal of Gynecology and Obstetrics*, 94 (3), 350-356
- Hochstenbach J** (2000) Rehabilitation is more than functional recovery. *Disability & Rehabilitation*, 22(4), 201-204
- Hoeman SP** (1997) Primary care for children with spina bifida. *Nurse Practitioner*, 22 (9), 60-62
- Hogan DP & Astone NM** (1986) The transition to adulthood. *Annual Review of Sociology*, 12, 109-130
- Hogan DP, Msall ME, Rogers ML & Avery RC** (1997) Improved disability population estimates of functional limitation among American children aged 5-17. *Maternal Child Health Journal*, 1(4), 203-16
- Hogansen JM, Powers K, Geenen S, Gil-Kashiwabara E & Powers L** (2008) Transition goals and experiences of females with disabilities: Youth, parents, and professionals. *Exceptional Children*, 74(2), 215-234
- Hogg J** (2001) Essential healthcare for people with learning disabilities: Barriers and opportunities. *Journal of the Royal Society of Medicine*, 94, 333-336
- Hollar D & Moore D** (2004) Relationship of substance use by students with disabilities to long-term educational, employment, and social outcomes. *Substance Use & Misuse*, 39(6), 931-962
- Holmes-Walker DJ, Llewellyn AC & Farrell K** (2007) A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15-25 years. *Diabet Med*, 24(7), 764-9
- Horvitz-Lennon M, Kilbourne AM & Pincus HA** (2006) From silos to bridges: Meeting the general health care needs of adults with severe mental illnesses. *Health Affairs*, 25(3), 659-69
- Hostler SL, Gressared RP, Hassler GR, & Linden PG** (1989) Adolescent autonomy project: Transition skills for adolescents with physical disability. *Children's Health Care*, 18, 12-18
- Houtrow AJ, Kim SE, Chen AY & Newacheck PW** (2007) Preventive health care for children with and without special health care needs. *Pediatrics*, 119, e821-8
- Houtrow AJ & Newacheck PW** (2008) Understanding transition issues: Asthma as an example. *J Pediatr*, 152(4), 453-5
- Hudsmith LE & Thorne SA** (2007) Transition of care from paediatric to adult services in cardiology. *Arch Dis Child*, 92(10), 927-30
- Hudson MM & Findlay S** (2006) Health-risk behaviors and health promotion in adolescent and young adult cancer survivors. *Cancer*, 107(S7 Aug 10), 1695-1701

- Hudson MM, Hester A, Sweeney T, Kippenbrock S, Majcina R, Vear S, Wiard S & Kaplan SJ** (2004) A model of care for childhood cancer survivors that facilitates research. *Pediatr Oncol Nursing*, 21(3), 170-4
- Hudson MM & Patte C** (2008) Education and health promotion in adolescent and young adult cancer survivors. *Pediatr Blood Cancer*, 50(5 Suppl), 1105-8
- Huffman D & Geber G** (1991) Youth with disabilities and chronic illness: An international annotated bibliography. *Pediatrician*, 18, 163-171
- Hughes C** (2001) Transition to adulthood: Supporting young adults to access social, employment, and civic pursuits. *Ment Retard Dev Disabil Res Rev*, 7(2), 84-90
- Hughes RB** (2006) Achieving effective health promotion for women with disabilities. *Family & Community Health*, 29(1):44S-51S, January/March
- Hulsman B & Chubon SJ** (1989) A comparison of disabled adults' perceived quality of life in nursing facility and home settings. *Public Health Nursing*, 6(3), 141-146
- Huyard C** (2008) Exploring one's own human condition: Adults affected by Cystic Fibrosis. *Qualitative Health Research*, 18 (4), 535-544
- Hwang W, Weller W & Ireys, H** (2001) Out-of-pocket medical spending for care of chronic conditions. *Health Affairs*, 20, 267-278
- Icard PF, Hower SJ, Kuchenreuther AR, Hooper SR & Gipson DS** (2008) The transition from childhood to adulthood with ESRD: Educational and social challenges. *Clin Nephrol*, 69(1), 1-7
- Iezzoni L** (2002) Using administrative data to study persons with disabilities. *The Milbank Quarterly*, 80 (2), 347-379
- Igoe C** (2000) Adolescents want control of their healthcare. *Exceptional Parent*, 30 (8) August
- Iitaka K, Motoyama O, Nakamura S, Koshino H & Sakai T** (2008) Transition of children with membranoproliferative glomerulonephritis to adolescence and adulthood. *Clin Exp Nephrol*, 12(1), 28-32
- Ikiugu M & Ciaravino EA** (2006) Assisting adolescents experiencing emotional and behavioral difficulties (EBD) transition to adulthood. *International Journal of Psychosocial Rehabilitation*, 10(2), 57-78
- Iles N & Lowton K** (2009) What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services? *Health Soc Care Community*. 2009 Jul 22. [Epub ahead of print]
- Insabella G, Grey M, Knafi G & Tamborlane W** (2007) The transition to young adulthood in youth with type 1 diabetes on intensive treatment. *Pediatr Diabetes*, 8(4), 228-34
- Ireys HT, Salkever DS, Kolodner KB, & Bijur PE** (1996) Schooling, employment, and idleness in young adults with serious physical conditions: Effects of age, disability status, and parental education. *Journal of Adolescent Health*, 19, 25-33
- Irvin LK, Thorin E & Singer GHS** (1993) Family-related roles and considerations: Transition to adulthood by youth with developmental disabilities. *Journal of Vocational Rehabilitation*, 3(2), 38-46
- Irvine T** (2004) Transitional care for young people with inflammatory bowel disease. *Gastrointestinal Nursing*, 2 (8), 25-28
- Jackson R & Pencharz PB** (2003) Transition of care between paediatric and adult gastroenterology. *Best Pract Res Clin Gastroenterol*, 17(2), 213-35
- Jacobs C, Zack J, Keenan P, Harney K, Austin SV, Colin A & Emans SJ** (2000) Transition to adulthood in a pediatric setting: Perspectives of patients with Cystic Fibrosis. *Journal of Adolescent Health*, 26 (2), 85
- Jain S** (2007) Teaching learners to care for children and youth with special health care needs. *Fam Med*, 39(2), 85-7
- James AM** (2007) Principles of youth participation in mental health services. *Med J Aust*, 187(7 Suppl), S57-60
- Janiga Sj & Costenbader V** (2002) The transition from high school to postsecondary education for students with learning disabilities: A survey of college service coordinators. *J Learn Disabil*, 35 (5), 462-8, 479

Jastrowski KE, Berlin KS, Sato AF & Davies WH (2007) Disclosure of attention-deficit/hyperactivity disorder may minimize risk of social rejection. *Psychiatry*, 70(3), 274-82

Jeppson E & Thomas J (1994) *Essential Allies: Families as Advisors*. Institute on Family Centered Care. Bethesda, MD

Jette AM & Keyson JJ (2002) Uses of evidence in disability outcomes and effectiveness research. *The Milbank Quarterly*, 80, (2), 325-345

Johnson CP (1995) Transition into adulthood. *Pediatric Annals*, 24, 268- 273

Johnson DR & Halloran WH (1997) The federal legislative context and goals of the state systems change initiative on transition for youth with disabilities *Career Dev Except Individ*, 20 (2), 109-121

Johnson JG, Chen H & Cohen P (2004) Personality disorder traits during adolescence and relationships with family members during the transition to adulthood. *Journal of Consulting and Clinical Psychology*, 72(6), 923-32

Johnson KL, Dudgeon B, Kuehn C & Walker W (2007) Assistive technology use among adolescents and young adults with spina bifida. *American Journal of Public Health*, 97(2), 330-6

Jones BL (2008) Promoting healthy development among survivors of adolescent cancer. *Fam Community Health*, 31 Suppl 1, S61-70

Jones R (1997) How can adolescents' health needs and concerns best be met? *British Journal of General Practice*, 47 (423), 631-634

Jones SE & Hamilton S (2008) The missing link: Paediatric to adult transition in diabetes services. *Br J Nursing*, 17(13), 842-7

Jonikas JA, Laris A & Cook JA (2003) The passage to adulthood: Psychiatric rehabilitation service and transition-related needs of young adult women with emotional and psychiatric disorders. *Psychiatr Rehabil J*, 27(2), 114-21

Jorm AF, Morgan AJ & Wright A (2008) First aid strategies that are helpful to young people developing a mental disorder: Beliefs of health professionals compared to young people and parents. *BMC Psychiatry*, 8(8), 42

Jorm AF & Wright A (2007) Beliefs of young people and their parents about the effectiveness of interventions for mental disorders. *Aust N Z J Psychiatry*, 41(8), 656-66

Judd A, Doerholt K, Tookey PA, Sharland M, Riordan A, Menson E, Novelli V, Lyall EG, Masters J, Tudor-Williams G, Duong T & Gibb DM; Collaborative HIV Paediatric Study (CHIPS); National Study of HIV in Pregnancy and Childhood (NSHPC) (2007) Morbidity, mortality, and response to treatment by children in the United Kingdom and Ireland with perinatally acquired HIV infection during 1996-2006: Planning for teenage and adult care. *Clin Infect Dis*, 45(7), 918-24

Kaestle CE & Halpern CT (2007) What's love got to do with it? Sexual behaviors of opposite-sex couples through emerging adulthood. *Perspectives on Sexual and Reproductive Health*, 39 (3), 134-140

Kalwinsky DK (2002) Health care issues as the child with chronic illness transitions to adulthood. *Southern Medical Journal*, 95, 966-967

Kardos M & White BP (2005) The role of the school-based occupational therapist in secondary education transition planning: A pilot survey study. *American Journal of Occupational Therapy*, 59(2), 173-80

Kato PM, Cole SW, Bradlyn AS & Pollock BH (2008) A video game improves behavioral outcomes in adolescents and young adults with cancer: A randomized trial. *Pediatrics*, 122(2), e305-17

Kaufman M (2006) Role of adolescent development in the transition process. *Prog Transplant*, 16(4), 286-90

Kaufman M (2006) Transition of cognitively delayed adolescent organ transplant recipients to adult care. *Pediatr Transplantation*, 10, 413-417

Kaufman M & Pinzon J (2007) Transition to adult care for youth with special health care needs. *Paediatrics and Child Health*, 9(12), 785-788

Keenan-Miller D, Hammen CL & Brennan PA (2007) Health outcomes related to early adolescent depression. *Journal of Adolescent Health*, 41(3), 256-62

- Kelly AM** (1995) The primary care provider's role in caring for young people with chronic illness. *Journal of Adolescent Health*, 17, 32-36
- Kelly AM, Kratz B, Bielski M & Rinehart RM** (2002) Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics*, 110 (6), 1322-1327
- Kelly CM, Jorm AF & Wright A** (2007) Improving mental health literacy as a strategy to facilitate early intervention for mental disorders. *Med J Aust*, 187(7 Suppl), S26-30
- Kelly KB** (2007) Promoting adolescent health. *Acta Paediatrica, International Journal of Paediatrics*, 96 (10), 1389-1391
- Kennedy A & Sawyer S** (2008) Transition from pediatric to adult services: Are we getting it right? *Curr Opin Pediatrics*, 20(4), 403-9
- Kennedy A, Sloman F, Douglass JA, & Sawyer SM** (2007) Young people with chronic illness: The approach to transition. *Intern Med Journal*, 37(8), 555-60. Comment in: *Intern Med J*. 2008 May, 38(5), 377-8; author reply 378-9.
- Kennedy S, Martin S, Kelley J, Walton B, Vicek C, Hassanein R & Holmes G** (1998) Identification of medical and nonmedical needs of adolescents and young adults with spina bifida and their families: A preliminary study. *Children's Health Care*, 27, 47-61
- Kent RM & Chamberlain MA** (2004) Transition from paediatric to adult neurological services. *J Neurol Neurosurg Psychiatry*, 75, 1208
- Kent RM & Chamberlain MA** (2003) Transition from paediatric to adult neurological services. *J Neurol Neurosurg Psychiatry*, 74(8), 1011-3
- Keogh BK, Bernheimer LP & Guthrie D** (2004) Children with developmental delays twenty years later: Where are they? How are they? *Am J Ment Retard*, 109(3), 219-30
- Keonning G, Benjamin J, Todaro A, Warren R & Burns M** (1995) Bridging the "Med-Ed Gap" for students with special health care needs: A model school liaison program. *Journal of School Health*, 65 (6), 207-212
- Kerman B, Barth RP & Wildfire J** (2004) Extending transitional services to former foster children. *Child Welfare*, 83(3), 239-62
- Kerr GRD** (2001) Assessing the needs of learning disabled young people with additional disabilities: Implications for planning adult services. *Journal of Learning Disabilities*, 5(2), 157-174
- Kim K-H & Turnbull A** (2004) Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons with Severe Disabilities*, 29 (1), 53-57
- King GA, Baldwin PJ, Currie M & Evans J** (2006) The effectiveness of transition strategies for youth with disabilities. *Children's Health Care*, 35(2), 155-178
- King GA, Baldwin PJ, Currie M & Evans J** (2005) Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care*, 34(3), 193-216
- King GA, Cathers T, Polgar JM, MacKinnon E & Havens L** (2000) Success in life for older adolescents with cerebral palsy. *Qualitative Health Research*, 10(6), 734-749
- King GA, Shultz LZ, Steel K, et al** (1993) Self evaluation and self concept of adolescents with physical disabilities. *American Journal of Occupational Therapy*, 47, 132-40
- Kingsnorth S, Healy H & Macarthur C** (2007) Preparing for adulthood: A systematic review of life skill programs for youth with physical disabilities. *Journal of Adolescent Health*, 41 (4), 323-332
- Kinne S, Patrick DL & Doyle DL** (2004) Prevalence of secondary conditions among people with disabilities. *American Journal of Public Health*, 94 (3), 443-445
- Kinney TR & Ware RE** (1996) Adolescent with Sickle Cell Anemia. *Hematology/ Oncology Clinics of North America*, 10(6), 1255-1263
- Kinney WB, & Coyle CP** (1992) Predicting life satisfaction among adults with physical disabilities. *Archives of Physical Medicine & Rehabilitation*, 73(9), 863-869

Kipps S, Bahu T, Ong K, Ackland FM, Brown RS, Fox CT, Griffin NK, Knight AH, Mann NP, Neil HA, Simpson H, Edge JA & Dunger DB (2002) Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabet Med*, 19, 649-54

Kirk J & Clayton P (2006) Specialist services and transitional care in paediatric endocrinology in the UK and Ireland. *Clin Endocrinol (Oxf)*, 65(1 Jul), 59-63

Kirk S (2008) Transitions in the lives of young people with complex healthcare needs. *Child Care Health Dev*, 34(5), 567-75

Klaas S & Hickey K (2001) Transition to adult care. *SCI Nursing*, 18(3), 158-60

Klein D (2003) Short report: Adolescents' health. Does having a family physician make a difference? *Canadian Family Physician*, 49, 1000-1002

Klein JD (2000) Adolescents, health services, and access to care. *Journal of Adolescent Health*, 27, 293-294

Klein JD, Handwerker L, Sesselberg TS, Sutter E, Flanagan E & Gawronski B (2007) Measuring quality of adolescent preventive services of health plan enrollees and school-based health center users. *Journal of Adolescent Health*, 41(2), 153-60

Klingbeil H, Baer HR & Wilson PE (2004) Aging with a disability. *Arch Phys Med Rehabil*, 85, (7 Suppl 3), S68-73.

Knapp M, Perkins M, Beecham J, Dhanasiri S & Rustin C (2008) Transition pathways for young people with complex disabilities: Exploring the economic consequences. *Child Care Health Dev*, 34(4), 512-20

Knauth A, Verstappen A, Reiss J & Webb GD (2006) Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease. *Cardiol Clin*, 24, 619-29, vi

Knauth Meadows A, Bosco V, Tong E, Fernandes S & Saidi A. (2009) Transition and transfer from pediatric to adult care of young adults with complex congenital heart disease. *Curr Cardiol Rep*, 11(4), 291-7

Ko B & McEnery G (2004) The needs of physically disabled young people during transition to adult services. *Child Care Health Development*, 30(4), 317-23

Koch LC (2000) Career development interventions for transition-age youths with disabilities. *Work*, 14(1), 3-11

Koch T (2000) The illusion of paradox: commentary on Albrecht, GL and Devlieger, PJ (1998). The disability paradox: high quality of life against all odds. *Social Science & Medicine*, 48, 977-988

Kogan MD & van Dyck PC (2005) Editorial: The National Survey of Children with Special Health Care Needs: Using state-level data to improve systems of care for children. *Maternal and Child Health Journal* 9S:s1-s2. Entire June 2005 supplement is on the National Survey of CSHCN – no papers specific to transition issues.

Kohler P & Rusch FR (1995) School to work transition: Identification of employment-related outcomes and activity indicators. *Career Development for Exceptional Individuals (CDEI)*, 18 (1), 33-50

Kohler P, DeStefano L, Wermuth T, Grayson T & McGinty S (1994) An analysis of exemplary transition programs: How and why are they selected? *Career Development for Exceptional Individuals (CDEI)*, 17, (2), 187-201

Kohler PD & Field S (2003) Transition-Focused Education: Foundation for the Future. *Journal of Special Education*, 37 (3), 174-183

Koller R (2000) Sexuality and adolescents with autism. *Sexuality and Disability*, 18, 2

Kollipara S & Kaufman FR (2008) Transition of diabetes care from pediatrics to adulthood. *School Nurse News*, 25(1), 27-9

Konsler GK & Jones GR (1993) Transition issues for survivors of childhood cancer and their health care providers. *Cancer Practice*, 1(4), 319-324

Kools S, Gilliss CL & Tong EM (1999) Family transitions in congenital heart disease management: The impact of hospitalization in early adulthood. *Journal of Family Nursing*, 5(4), 404-425

Kopac CA (2002) Gynecological and reproductive healthcare for women with special needs. *The Exceptional Parent*, 32(10), 78-83

- Kosht M & Dorn L** (1996) Continuing care for adult patients with Sickle Cell Anemia. *Hematology/ Oncology Clinics of North America*, 10(6), 1265-1273
- Kovacs AH, Silversides C, Saidi A & Sears SF** (2006) The role of the psychologist in adult congenital heart disease. *Cardiol Clin*, 24(4), 607-18, vi.
- Krauss MW, Gulley S, Sciegaj M & Wells N** (2003) Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation*, 41 (5), 329-339
- Kregel J & Wehman P** (1989) Supported Employment: Promises deferred for persons with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 14, 293-303
- Kriegsman KH, Zaslow E & D-Zmura-Rechsteiner J** (1992) *Taking Charge: Teenagers Talk About Life and Physical Disabilities*. Woodbine House
- Kroner MJ** (2007) The role of housing in the transition process of youth and young adults: A twenty-year perspective. *New Dir Youth Dev*, 113 (Spring), 51-75, 11
- Kruse B, Riepe FG, Krone N, Bosinski HA, Kloehn S, Partsch CJ, Sippell WG & Monig H** (2004) Congenital adrenal hyperplasia - how to improve the transition from adolescence to adult life. *Exp Clin Endocrinol Diabetes*, 112(7), 343-55
- Kubick B** (2003) Families in transition: A child spreads his wings. *HEMAware*, 8 (4), 56-58
- Kyngas H** (2003) Patients education: Perspective of adolescents with a chronic disease. *Journal of Clinical Nursing*, 12, 744-751
- Kyngas HA, Kroll T & Duffy ME** (2000) Compliance in adolescents with chronic diseases: A review. *Journal of Adolescent Health*, 26, 379-388
- Kyunghwa K** (2003) Adolescents and their parents: A Review of intergenerational family relations for immigrant and non-immigrant families. *Human Development*, 46, 115-136
- La Greca AM, Auslander WF & Greco P** (1995) I get by with a little help from my family and friends: Adolescents' support for diabetes care. *J Pediatr Psychol*, 20, 449-476
- La Greca AM, Bearman KJ & Moore H** (2002) Peer relations of youth with pediatric conditions and health risks: Promoting social support and healthy lifestyles. *Journal of Developmental and Behavioral Pediatrics*, 23 (4), 271-280
- Laidlaw TS, Kaufman DM, Sargeant J, MacLeod H, Blake K & Simpson D** (2007) What makes a physician an exemplary communicator with patients? *Patient Education and Counseling*, 68 (2), 153-160
- Lakdawalla DN, Bhattacharya J & Goldman DP** (2004) Are the young becoming more disabled? *Health Affairs*, 23, 168-176
- Lam PY, Fitzgerald BB & Sawyer SM** (2005) Young adults in children's hospitals: Why are they there? *Medical Journal Australia*, 182(8), 381-4
- Landau L** (1995) Cystic fibrosis: Transition from paediatric to adult physician's care. *Thorax*, 50(10), 1031-2
- Lange K, Sassmann H, von Schütz W, Kordonouri O & Danne T** (2007) Prerequisites for age-appropriate education in type 1 diabetes: A model programme for paediatric diabetes education in Germany. *Pediatr Diabetes*, 8 (Suppl 6), 63-71
- Lau S** (2008) Transition from childhood to adult asthma. *Lancet*, 372(9643), 1014-5
- Lawrence K, Stillely CS, Olshansky E, Bender A & Webber SA** (2008) Further exploration: Maturity and adherence in adolescent and young adult heart transplant recipients. *Prog Transplant*, 18(1), 50-4
- Lawson S, & Everson JM** (1994) A national review of statements of transition services for students who are deaf-blind. Sands Point, NY: Helen Keller National Center, Technical Assistance Center
- Lee C & Gramotnev H** (2007) Life transitions and mental health in a national cohort of young Australian women. *Developmental Psychology*, 43(4), 877-888

- Lee JM, Okumura MJ, Freed GL, Menon RK & Davis MM** (2007) Trends in hospitalizations for diabetes among children and young adults: United States, 1993 -2004. *Diabetes Care*, 30(12), 3035-9
- Lee P, Greenfield JR & Campbell LV** (2009) Managing young people with Type 1 diabetes in a 'rave' new world: Metabolic complications of substance abuse in Type 1 diabetes. *Diabet Med*, 26(4), 328-33
- Lee PJ** (2002) Growing older: The adult metabolic clinic. *J Inherit Metab Dis*, 25(3), 252-60
- Lee S, Juon HS, Martinez G, Hsu CE, Robinson ES, Bawa J & Ma GX** (2009) Model minority at risk: Expressed needs of mental health by Asian American young adults. *J Community Health*, 34 (2), 144-152
- Lee YL, Santacroce SJ & Sadler L** (2007) Predictors of healthy behaviour in long-term survivors of childhood cancer. *J Clin Nursing*, 16(11C), 285-95
- Lehman AF** (1995) Measuring quality of life in a reformed health system. *Health Affairs*, 14(3), 90-101
- Lenz B** (2001) The transition from adolescence to young adulthood: A theoretical perspective. *Journal of School Nursing*, 17, 300-6
- Lewis-Gary MD** (2001) Transitioning to adult health care facilities for young adults with a chronic condition. *Pediatric Nursing*, 27, 521-4
- Liebert D, Lutsky L & Gottlieb A** (1990) Postsecondary experiences of young adults with severe disabilities. *Exceptional Children*, 56, 56-63
- Lindeke LL, Leonard BJ, Presler B & Garwick A** (2002) Family-centered care coordination for children with special needs across multiple settings. *J Pediatr Health Care*, 16(6), 290-7
- Lindstrom B & Kohler L** (1991) Youth, disability and quality of life. *Pediatrician*, 18(2), 121-128
- Lindström K, Winblad B, Haglund B & Hjern A** (2007) Preterm infants as young adults: A Swedish national cohort study. *Pediatrics*, 120(1), 70-7; erratum in *Pediatrics*, 120(4), 936
- Lindvall K, Colstrup L & Wollter IM** (2006) Compliance with treatment and understanding of own disease in patients with severe and moderate haemophilia. *Haemophilia*, 12 (1), 47-51
- Linroth R** (2009) Meeting the needs of young people and adults with childhood-onset conditions: Gillette Lifetime Specialty Healthcare. *Dev Med Child Neurol*, 51, Oct Suppl 4, 174-7
- Linthorst Homan MW, de Korte J, Grootenhuis MA, Bos JD, Sprangers MA & van der Veen JP** (2008) Impact of childhood vitiligo on adult life. *Br J Dermatol*, 159(4), 915-20
- Liptak GS, Orlando M, Yingling JT, Theurer-Kaufman KL, Malay D, Tompkins LA & Flynn JR** (2006) Satisfaction with primary health care received by families of children with developmental disabilities. *Journal of Pediatric Health Care*, 20 (4), 245-252
- Litt IF** (1995) Moving on: Who is on-board? *J Adolesc Health*, 17, 1
- LoCasale-Crouch J & Johnson B** (2005) Transition from pediatric to adult medical care. *Advances in Chronic Kidney Disease*, 12 (4), 412-7
- Lollar DJ** (1994) Preventing secondary conditions associated with spina bifida or cerebral palsy: Proceedings and recommendations of a symposium. Washington, DC: Spina Bifida Association of America
- Loney BR, Taylor J, Butler MA & Iacono WG** (2007) Adolescent psychopathy features: 6-year temporal stability and the prediction of externalizing symptoms during the transition to adulthood. *Aggress Behavior*, 33(3), 242-52
- Lopez P & Allen PJ** (2007) Addressing the health needs of adolescents transitioning out of foster care. *Pediatric Nursing*, 33(4), 345-55
- Lotstein DS, Ghandour R, Cash A, McGuire E, Strickland B & Newacheck P** (2009) Planning for health care transitions: Results from the 2005-2006 National Survey of Children With Special Health Care Needs. *Pediatrics*, 123(1), e145-52

- Lotstein DS, Inkelas M, Hays RD, Halfon N & Brook R** (2008) Access to care for youth with special health care needs in the transition to adulthood. *Journal of Adolescent Health*, 43(1), 23-9; comment pp 6-7
- Lotstein DS, McPherson M, Strickland B & Newacheck PW** (2005) Transition planning for youth with special health care needs: Results from the National Survey of Children with Special Health Care Needs. *Pediatrics*, 115, 1562-8
- Loux TJ, Haricharan RN, Clements RH, Kolotkin RL, Bledsoe SE, Haynes B, Leath T & Harmon CM** (2008) Health-related quality of life before and after bariatric surgery in adolescents. *J Pediatr Surgery*, 43(7), 1275-9
- Luft P** (1999) Assessment and collaboration: Key elements in comprehensive and cohesive transition planning. *Work*, 13(1), 31-41
- Luft P & Koch LC** (1998) Transition of adolescents with chronic illness: Overlooked needs and rehabilitation considerations. *Journal of Vocational Rehabilitation*, 10(3), 205-217
- Luft P, Rumrill P, Snyder JL & Hennessey M** (2001) Transition strategies for youths with sensory impairments: Educational, vocational, and independent living considerations. *Work*, 17, 125-134
- Lukomski J** (2007) Deaf college students' perceptions of their social-emotional adjustment. *J Deaf Stud Deaf Educ*, 12: 486-494
- Lunsky Y, Straiko A & Armstrong S** (2003) Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16(4), 247-253
- Lutenbacher M, Karp S, Ajero G, et al** (2005) Crossing community sectors: Challenges faced by families of children with special health care needs. *J Fam Nursing*, May, 11(2), 162-82
- Luther B** (2001) Age-specific activities that support successful transition to adulthood for children with disabilities. *Orthopaedic Nursing*, 20 (1), 23-9
- Lynch C, Matthews R & Rosina R** (2007) Health as a mediator of change in the trajectory of young people in contact with the criminal justice system. *Int J Adolesc Med Health*, 19(3), 269-76
- Lynch T & Spence D** (2008) A qualitative study of youth living with Crohn disease. *Gastroenterol. Nursing*, 31(3), 224-30; quiz 231-2
- Lyon ME, Kuehl K & McCarter R** (2006) Transition to adulthood in congenital heart disease: Missed adolescent milestones. *Journal of Adolescent Health*, 39 (1 Jul), 121-4
- MacLean WE Jr, Foley GV, Ruccione K & Sklar C** (1996) Transitions in the care of adolescent and young adult survivors of childhood cancer. *Cancer*, 78, 1340-1344
- MacMillan D, Widaman K, Balow I, BorthwickDuffy S, Hendrick I & Hemsley R** (1992) Special education students exiting the educational system. *Journal of Special Education*, 26(1), 20-36
- Madge S & Bryon M** (2002) A model for transition from pediatric to adult care in cystic fibrosis. *J Pediatr Nursing*, 17, 283-8
- Magill-Evans J, Darrah J, Pain K, Adkins R & Kratochvil M** (2001) Are families with adolescents and young adults with cerebral palsy the same as other families. *Developmental Medicine and Child Neurology*, 43, 466-472
- Magill-Evans J, Wiart L, Darrah J, et al.** (2005) Beginning the transition to adulthood: The experiences of six families with youths with cerebral palsy. *Phys Occup Ther Pediatr*, 25(3), 19-36
- Mallory B** (1995) The role of social policy in life-cycle transition. *Exceptional Children*, 62, 213-233
- Mann NR** (1997) Primary care for persons with disabilities: The Rehabilitation Institute of Michigan Model Program. *Am J Phys Med Rehabil*, 76, S47-9
- Manteuffel B, Stephens RL, Sondheimer DL & Fisher SK** (2008) Characteristics, service experiences, and outcomes of transition-aged youth in systems of care: Programmatic and policy implications. *Journal of Behavioral Health Services and Research*, 35(4), 469-487
- Maradiegue A** (2002) The Health Insurance Portability and Accountability Act and adolescents. *Pediatric Nursing*, 28 (4), 417-420

- Marcell AV, Klein JD, Fischer I, Allan MJ & Kokotailo PK** (2002) Male adolescent use of health care services: Where are the boys? *Journal of Adolescent Health*, 30, 35-43
- Marcer H, Finlay F & Baverstock A** (2008) ADHD and transition to adult services--the experience of community paediatricians. *Child Care Health Dev*, 34(5), 564-6
- Marks B & Heller T** (2003) Bridging the equity gap: Health promotion for adults with intellectual and developmental disabilities. *Nursing Clinics of North America*, 38 (2), 205-228
- Marn LM & Koch LC** (1999) The major tasks of adolescence: Implications for transition planning with youths with cerebral palsy. *Work*, 13 (1), 51-58
- Martin C** (1996) Meeting the needs of children and families in chronic illness and disease: A greater role for the GP. *Australian Family Physician*, 25(8), 1273-1281
- Masten AS, Burt KB, Roisman GI, Obradovic J, Long JD & Tellegen A** (2004) Resources and resilience in the transition to adulthood: Continuity and change. *Developmental Psychopathology*, 16(4), 1071-94
- Matarese M, McGinnis L & Mora M** (2004) Youth involvement in systems of care: A guide to empowerment. Technical Assistance Partnership. Downloadable at http://www.tapartnership.org/docs/Youth_Involvement.pdf
- Maternal and Child Health Bureau** (1992) Moving on: Transition from child-centered to adult health care. Rockville, MD: Maternal and Child Health Bureau, U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration
- Maternal and Child Health Bureau, DSCSHN, HRSA** (1999) National Agenda for Children with Special Health Care Needs: Measuring Success for Healthy People 2010: A Working Document, EIRI, Utah State University
- Maunder EZ** (2004) The challenge of transitional care for young people with life-limiting illness. *British Journal of Nursing*, 13 (10), 594-596
- May J** (1999) Maine: Young people and their health care needs. Counterpoint, Summer 1999
- McAllister J, Presler E, Turchi R & Antonelli R** (2009) Achieving effective care coordination in the medical home. *Pediatric Annals*, 38 (9), 491-497
- McAllister JW, Presler E & Cooley WC** (2007) Practice-based care coordination: A medical home essential. *Pediatrics*, 120, e723-33
- McArnarney E** (1985) Social maturation: A challenge for handicapped and chronically ill adolescents, *Adolescent Health Care*, 6, 90-101
- McCarthy P, Everson J & Barcus M** (1985) School to Work Transition for Youth with Severe Disabilities (Monograph) Richmond, VA: Commonwealth University, Project Transition Into Employment
- McCauley AP, Salter C, Kiragu K & Senderowitz J** (1995) Meeting the needs of young adults. Population reports. Series J: Family planning programs, (41), 1-43
- McClanahan KK** (2006) Special needs call for specialized services: A response to no need to specialize: Reproductive health is for all adolescents. *J Pediatr Adolesc Gynecol*, 19(2), 109-12
- McCracken M, Jiles R & Blanck HM** (2007) Health behaviors of the young adult U.S. population: Behavioral risk factor surveillance system, 2003. *Prev Chronic Diseases*, 4(2), A25
- McCurdy C, DiCenso A, Boblin S, Ludwin D, Bryant-Lukosius D & Bosompra K** (2006) There to here: Young adult patients' perceptions of the process of transition from pediatric to adult transplant care. *Prog Transplant*, 16(4), 309-16
- McCutcheon LK, Chanen AM, Fraser RJ, Drew L & Brewer W** (2007) Tips and techniques for engaging and managing the reluctant, resistant or hostile young person. *Med J Aust*, 187(7 Suppl), S64-7
- McDonagh JE** (2008) Young people first, juvenile idiopathic arthritis second: Transitional care in rheumatology. *Arthritis Rheum*, 59(8), 1162-70; comment pp 1054-7
- McDonagh JE** (2007) Transition of care from paediatric to adult rheumatology. *Arch Dis Child*, 92, 802-7
- McDonagh JE** (2005) Growing up and moving on: Transition from pediatric to adult care. *Pediatric Transplantation*, 9 (3), 364-72

McDonagh, JE (2000) The adolescent challenge. *Nephrol Dial Transplant*, 15, 1761-1765

McDonagh JE, Foster HE, Hall MA & Chamberlain MA (2000) Audit of rheumatology services for adolescents and youth adults in the UK. *Rheumatology*, 39, 596-602

McDonagh JE & Kaufman M (2009) Transition from pediatric to adult care after solid organ transplantation. *Curr Opin Organ Transplant*, Jul 15. [Epub ahead of print]

McDonagh JE & Kelly DA (2003) Transitioning care of the pediatric recipient to adult caregivers. *Pediatric Clinics North America*, 50(6), 1561-83, xi-xii

McDonagh JE, Minaar G, Kelly K, O'Connor D & Shaw KL (2006) Unmet education and training needs in adolescent health of health professionals in a UK children's hospital. *Acta Paediatr*, 95, 715-9

McDonagh JE, Southwood T & Ryderz C (2000) Bridging the gap in rheumatology. *Annals of Rheumatological Disease*, 59, 86-93

McDonagh JE, Southwood TR & Shaw KL (2007) The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology*, 46 (1), 161-168

McDonogh JE, Shaw KL & Southwood TR (2006) Growing up and moving on in rheumatology: Development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *Journal of Child Health Care*, 10 (1), 22-42

McDonagh JE, Southwood TR & Shaw KL (2004) Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology*, 43, 737-743

McDonagh JE & Viner RM (2006) Lost in transition? Between paediatric and adult services. *BMJ*, 332(7539), 435-6

McDonagh JE & White PH (Eds) (2008) *Adolescent Rheumatology*. Informa HealthCare

McGill M (2002) How do we organize smooth, effective transfer from paediatric to adult diabetes care? *Horm Res*, 57 (Suppl 1), 66-8

McGoldrick D, Neal C & Whiteson M (2008) Advocacy and adolescent/young adult cancer survivors. *Pediatr Blood Cancer*, 50(5 Suppl), 1109-11

McGorry PD (2007) The specialist youth mental health model: Strengthening the weakest link in the public mental health system. *Med J Australia*, 187(7 Suppl):S53-6; comment in 188(8), 492; author reply 492-3

McInerney CA & McInerney M (1994) Occupational therapy and school-to-work transition: A preventive education model. *Occupational Therapy International*, 1(3), 158-173

McLaughlin SE, Diener-West M, Indurkha A, Rubin H, Heckmann R & Boyle MP (2008) Improving transition from pediatric to adult cystic fibrosis care: Lessons from a national survey of current practices. *Pediatrics*, 121(5), e1160-6

McMahon R & Baer R (2001) IDEA transition policy compliance and best practice: Perceptions of transition stakeholders. *Career Development for Exceptional Individuals*, 24, 169-184

McManus MA, Newacheck PW & Greaney AM (1990) Young adults with special health care needs: Prevalence, severity and access to health services. *Pediatrics*, 86, 674-682

McNamara J (1997) Chronic illness in adolescents: Transfer or transition to adult services. *Journal of Paediatrics and Child Health*, 33, 460

McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP & Strickland B (1998) A new definition of children with special health care needs. *Pediatrics*, 102, 137-140

McPherson M & Honberg L (2002) Identification of children with special health care needs: A cornerstone to achieving Healthy People 2010. *Ambulatory Pediatrics*, 2, 22-23

McPherson A, Macfarlane A & Allen J (1996) What do young people want from their GP? *Br J Gen Pract*, 46 (411), 627

- McPherson M, Thaniel L & Minniti CP** (2009) Transition of patients with sickle cell disease from pediatric to adult care: Assessing patient readiness. *Pediatr Blood Cancer*, 52(7), 838-41
- McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ & Newacheck PW** (2004) Implementing community-based systems of services for children and youths with special health care needs: How well are we doing? *Pediatrics*, 113(5 Suppl), 1538-44
- Meeske KA & Nelson MB** (2008) The role of the long-term follow-up clinic in discovering new emerging late effects in adult survivors of childhood cancer. *J Pediatr Oncol Nursing*, 25(4), 213-9
- Megivern D, Pellerito S & Mowbray C** (2003) Barriers to higher education for individuals with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 26(3), 217-231
- Melgar T, Brands C & Sharma N** (2005) Health care transition. *Pediatrics*, 115, 1449-50
- Melgar T, Chamberlain JK, Cull WL, Kaelber DC & Kan BD** (2006) Training experiences of US combined internal medicine and pediatrics residents. *Academic Medicine*, 81 (5), 440-446
- Merrick J & Kandel I** (2003) Adolescents with special needs and the transition from adolescent to adult health care. *Int J Adolesc Med Health*, 15(2), 103
- Merrick J, Kandel I & Vardi G** (2004) Adolescents with Down Syndrome. *Int J Adolesc Med Health*, 16, 13-9
- Meyers AR, Glover M & Master RJ** (1997) Primary care for persons with disabilities: The Boston, Massachusetts Model Program. *Am J Phys Med Rehabil*, 76, S37-42
- Michaud PA, Suris JC & Viner R** (2004) The adolescent with a chronic condition, part II: Healthcare provision. *Arch Dis Child*, 89 (10), 943-9
- Miech RA, Caspi A, Moffitt TE, et al.** (1999) Low socioeconomic status and mental disorders: A longitudinal study of selection and causation during young adulthood. *American Journal of Sociology*, 104, 1096–1131
- Miles K, Edwards S & Clapson M** (2004) Transition from paediatric to adult services: Experiences of HIV-positive adolescents. *AIDS Care*, 16(3), 305-14
- Milbrath C** (2008) Caring for an underserved population: Helping pediatric patients with disabilities transition to adulthood. *Creat Nurs*, 14(2), 66-9
- Milliken S** (2007) Neurofibromatosis: A young woman's journey--case study. *J Neurosci Nursing*, 39(6), 332-5
- Miller S** (1996) Transition of care in adolescents. *Pediatric Nursing*, 8 (9), 14-16
- Millstein SG, Peterson AC & Nightingale EO** (1994) *Promoting adolescent health*. New York: Oxford University Press
- Minicozzi A** (2000) Transition to adult care: Another view. *Pediatric Nursing*, 26(4), 411-2
- Mitchell JM & Gaskin DJ** (2004) Do children receiving Supplemental Security Income who are enrolled in Medicaid fare better under a fee-for-service or comprehensive capitation model? *Pediatrics*, 114(1), 196-204
- Montgomery H, Persson LO & Ryden A** (1996) Importance and attainment of life values among disabled and non-disabled people. *Scandinavian Journal of Rehabilitation Medicine*, 28(4), 233-240
- Montgomery P, Donkoh C & Underhill K** (2006) Independent living programs for young people leaving the care system: The state of the evidence. *Children and Youth Services Review*, 28(12), 1435-1448
- Moons P, DeVolder E & Budts W** (2001) What do adult patients with congenital heart disease know about their disease, treatment, and prevention of complications? A call for structured patient education. *Heart*, 86, 74-80
- Moons P, Hilderson D & Van Deyk K** (2008) Implementation of transition programs can prevent another lost generation of patients with congenital heart disease. *Eur J Cardiovasc Nurs*, 7(4), 259-63; comment on 264-8.

- Moons P, Pinxten S, Dedroog D, Van Deyk K, Gewillig M, Hilderson D & Budts W** (2009) Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *J Adolesc Health*. 44(4):316-22; comment on 307-8
- Moore LA** (2007) Intimacy and multiple sclerosis. *Nursing Clinics of North America*, 42(4), 605-19; vii
- Morningstar ME** (1997) Critical issues in career development and employment preparation for adolescents with disabilities. *Remedial Spec. Educ*, 18 (5), 307-320
- Morningstar ME, Turnbull AP & Turnbull HR** (1995) What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? *Exceptional Children*, 62(3), 249-260
- Morningstar ME, Turnbull III HR, Lattin DL, Umbarger III GT, Reichard A & Moberly RL** (2001) Students supported by medical technology: Making the transition from school to adult life. *Journal of Developmental and Physical Disabilities*, 13 (3), 229-259
- Morris RI** (2007) Voices of foster youths: Problems and ideas for change. *Urol Nursing*, 27(5), 419-27
- Mortimer, JT & Staff J** (2004) Early work as a source of developmental discontinuity during the transition to adulthood. *Developmental Psychopathology*, 16(4), 1047-70
- Mudrick NR** (2002) The prevalence of disability among children: Paradigms and estimates. *Phys Med Rehabil Clin N Am*, 13(4), 775-92, vii
- Mukherjee S** (2007) Transition to adulthood in spina bifida: changing roles and expectations. *ScientificWorldJournal*, 26(7), 1890-5
- Mulvihill BA, Cotton JN & Gyaben SL** (2004) Best practices for inclusive child and adolescent out-of-school care: A review of the literature. *Family and Community Health*, 27 (1), 52-64
- Mulye TP, Park MJ, Nelson CD, Adams SH, Irwin CE & Brindis CD** (2009) Trends in adolescent and young adult health in the United States. *Journal of Adolescent Health*, 45(1), 8-24
- Murphy DJ Jr, Foster E, American College of Cardiology Foundation, American Heart Association, American College of Physicians Task Force on Clinical Competence (ACC/AHA/AAP Writing Committee to Develop Training Recommendations for Pediatric Cardiology** (2005) ACCF/AHA/AAP recommendations for training in pediatric cardiology. Task Force 6: Training in transition of adolescent care and care of the adult with congenital heart disease. *J Am Coll Cardiology*, 46(7), 1399-401
- Murphy K** (1999) Medical problems in adults with Cerebral Palsy: Case example. *Assistive Technology*, 11, 97-104
- Murphy KP, Molnar GE & Lankasky K** (2000) Employment and social issues in adults with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, 81, 807-811
- Murphy N & Young PC** (2005) Sexuality in children and adolescents with disabilities. *Developmental Medicine & Child Neurology*, 47(9), (640-644
- Murray C** (2003) Risk factors, protective factors, vulnerability, and resilience: A framework for understanding and supporting the adult transitions of youth with high-incidence disabilities. *Remedial and Special Education*, 24(1), 16-26
- Myers PS** (2002) Transitioning an adolescent dialysis patient to adult health care. *Nephrol Nurs J*, 29, 375-6
- Nagel K, Wizowski L, Duckworth J, Cassano J, Hahn SA & Neal M** (2008) Using plain language skills to create an educational brochure about sperm banking for adolescent and young adult males with cancer. *J Pediatr Oncol Nursing*, 25(4), 220-6
- Nakhala M, Daneman D, Frank M & Guttmann A** (2008) Translating transition: A critical review of the diabetes literature. *J Pediatr Endocrinol Metab*, 21(6), 507-16
- Nasr S, Campbell C & Howatt W** (1992) Transition program for pediatric to adult care for cystic fibrosis patients. *Journal of Adolescent Health*, 13, 682-685
- Nassau JH & Drotar D** (1997) Social competence among children with central nervous system-related chronic health conditions: A review. *J Pediatr Psychol*, 22, 771-793

National Center for Youth with Disabilities (1998) CYDLINE Reviews: A perspective on changes in health care for children and youth with special health needs, University of Minnesota, Box 721, 420 Delaware St. SE, Minneapolis, MN 55455

National Center for Youth with Disabilities (1995) Transition from Child to Adult Health Care Services: A National Survey, The National Center for Youth with Disabilities, University of Minnesota, Box 721, 420 Delaware St. SE, Minneapolis, MN 55455

National Center for Youth with Disabilities (1993) Teenagers at risk: A national perspective of state level services for adolescents with chronic illness or disability. Minneapolis, MN: University of Minnesota

Neece CL, Kraemer BR & Blacher J (2009) Transition satisfaction and family well being among parents of young adults with severe intellectual disability. *Intellect Dev Disabil*, 47(1), 31-43

Needham BL (2007) Gender differences in trajectories of depressive symptomatology and substance use during the transition from adolescence to young adulthood. *Soc Sci Med*, 65(6), 1166-79

Nehring WM & Faux SA (2006) Transitional and health issues of adults with neural tube defects. *Journal of Nursing Scholarship*, 38(1), 63-70

Neill L (2007) Patient involvement. Young clients can become the boss. *Health Serv Journal*, 117(6078), 30-1

Nelson LJ, Padilla-Walker LM, Carroll JS, Madsen SD, Barry CM & Badger S (2007) "If you want me to treat you like an adult, start acting like one!" Comparing the criteria that emerging adults and their parents have for adulthood. *J Fam Psychol*, 21(4), 665-74

Nelson MB & Meeske K (2005) Recognizing health risks in childhood cancer survivors. *J Am Acad Nurse Pract*, 17(3), 96-103

Neri MT & Kroll T (2003) Understanding the consequences of access barriers to health care: Experiences of adults with disabilities. *Disabil Rehabil*, 25, 85-96

Neuberger JM (2003) Transition of care between paediatric and adult gastroenterology: Liver transplantation. *Best Pract Res Clin Gastroenterol*, 17(2), 277-89

Neubert DA, Moon MS & Grigal M (2004) Activities of students with significant disabilities receiving services in postsecondary settings. *Education and Training in Developmental Disabilities*, 39(1), 16-25

Neufeld JA, Klingbeil F, Bryen DN, Silverman B & Thomas A (2002) Adolescent sexuality and disability. *Phys Med Rehabil Clin N Am*, 13(4), 857-73

Neumark-Sztainer D, Blum RWM, Brindis CD, Anglin TM & Irwin CE (1997) The state of adolescent health: Looking back and planning ahead. *Journal of Adolescent Health*, 21 (5), 280-286

Newacheck PW (1992) Adolescents with special needs: Prevalence, severity, and access to health services. *Pediatrics*, 84, 872-881

Newacheck PW & Halfon N (1998) Prevalence and impact of disabling chronic conditions in childhood. *American Journal of Public Health*, 88, 610-617

Newacheck PW, Hung YY, Park MJ, Brindis CD & Irwin Jr CE (2003) Disparities in adolescent health and health care: Does socioeconomic status matter? Access and quality. *Health Services Research*, 38 (5), 1235-1252

Newacheck PW & Kim SE (2005) A national profile of health care utilization and expenditures for children with special health care needs. *Arch Pediatr Adolesc Med*, 159, 10-17

Newacheck PW, Kim SE, Blumberg SJ & Rising JP (2008) Who is at risk for special health care needs: Findings From the National Survey of Children's Health. *Pediatrics*, 122, 347-359

Newacheck PW, Strickland B, Skonkoff JP, Perrin JM, McPherson M, McManus M, Lauver C & Fox H (1998) An epidemiological profile of children with special health care needs. *Pediatrics*, 102 (1), 117-123

Newland JA (2008) Factors influencing independence in adolescents with sickle cell disease. *J Child Adolesc Psychiatr Nurs*, 21(3), 177-85

- Nicholson JL, Collins SR, Mahato B, Gould E, Schoen C & Rustgi SD** (2009) Rite of Passage? Why Young Adults Become Uninsured and How New Policies Can Help, 2009 Update, The Commonwealth Fund, August 6, 2009 | Volume 64 <http://www.commonwealthfund.org/Content/Publications/Issue-Briefs/2009/Aug/Rite-of-Passage-Why-Young-Adults-Become-Uninsured-and-How-New-Policies-Can-Help-2009-Update.aspx>
- Nieuwenhuijsen C, van der Laar Y, Donkervoort M, Nieuwstraten W, Roebroek ME & Stam HJ** (2008) Unmet needs and health care utilization in young adults with cerebral palsy. *Disabil Rehabil*, 30(17), 1254-62
- Nixon G, Glazner J & Martin J** (2003) Female sexual health care in cystic fibrosis. *Aren Dis Child*, 88, 265-266
- Noll RB, Gartstein MA & Vannatta K** (1999) Social, emotional, and behavioral functioning of children with cancer. *Pediatrics*, 103, 71-78
- Noll RB, LeRoy S & Bukowski WM** (1991) Peer relationships and adjustment of children with cancer. *J Pediatr Psychol*, 16, 307-326
- Noll RB, Vannatta K & Koontz K** (1996) Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Dev*, 67, 423-436
- Nordli DR** (2001) Special needs of the adolescent with epilepsy. *Epilepsia*, 42, 8, 10-17
- Nosek MA** (1992) Point of view: Primary care issues for women with severe physical disabilities. *J Women's Health*, 1, 245-8
- Nosek MA & Howland CA** (1997) Breast and cervical cancer screening among women with physical disabilities. *Arch Phys Med Rehabil*, 78, S-39-S-44
- Nosek MA, Hughes RB, Howland CA, Young ME, Mullen PD & Shelton ML** (2004) The meaning of health for women with physical disabilities: A qualitative analysis. In J. Lancaster (Ed.), *Crossing barriers to health: Disability issues within the family and community* [Feature Issue]. *Family and Community Health*, 27(1), 6-21
- Nosek MA & Parker RM** (1987) Psychosocial independence and functional abilities: Their relationship in adults with severe musculoskeletal impairments. *Archives of Physical Medical Rehabilitation*, 68, 840-845
- Noyes-Grosser DM** (2007) Children and youth with disabilities and public health: A model syllabus for health professionals. *Infants and Young Children*, 20 (3), 202-221
- Nutt DJ, Fone K, Asherson P, Bramble D, Hill P, Matthews K, Morris KA, Santosh P, Sonuga-Barke E, Taylor E, Weiss M & Young S** (2007) Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: Recommendations from the British Association for Psychopharmacology. *J Psychopharmacol*, 21(1), 10-41
- Oberg CN, Bryant NA & Bach ML** (1994) Ethics, values, and policy decisions for children with disabilities: What are the costs of political correctness? *Journal of School Health*, 64, 223-228
- O'Brien G** (2006) Young adults with learning disabilities: A study of psychosocial functioning at transition to adult services. *Dev Med Child Neurol*, 48(3), 195-9
- O'Connell B, Bailey S & Pearce J** (2003) Straddling the pathway from paediatrician to mainstream health care: Transition issues experienced in disability care. *Aust J Rural Health*, 11(2), 57-63
- O'Connell D** (1998) Teenagers move on. *Hemalog*, April, 9-12
- O'Day B, Dautel P & Scheer J** (2002) Barriers to healthcare for people with mobility impairments. *Manag Care Q*, 10(3), 41-51
- Oeffinger K, Eshelman D, Tomlinson G & Buchanan G** (1998) Programs for adult survivors of childhood cancer. *Journal of Clinical Oncology*, 16(8), 2864-67
- Oktaş K & Sönmezer M** (2008) Fertility issues and options in young women with cancer. *Recent Results Cancer Res*, 178, 203-24
- Okumura MJ, Heisler M, Davis MM, Cabana MD, Demonner S & Kerr EA** (2008) Comfort of general internists and general pediatricians in providing care for young adults with chronic illnesses of childhood. *J Gen Intern Med*, 23(10), 1621-7

Okumura MJ, McPheeters ML & Davis MM (2007) State and national estimates of insurance coverage and health care utilization for adolescents with chronic conditions from the National Survey of Children's Health, 2003. *Journal of Adolescent Health*, 41 (4), 343-349

O'Leary C, Wieneke P, Healy M, Cronin C, O'Regan P & Shanahan F (2004) Celiac disease and the transition from childhood to adulthood: A 28-year follow-up. *American Journal of Gastroenterology*, 99(12), 2437-2441

Olsen DG & Swigonski NL (2004) Transition to adulthood: The important role of the pediatrician. *Pediatrics*, 113, 159-163

Olsen PR & Harder I (2009) Keeping their world together-meanings and actions created through network-focused nursing in teenager and young adult cancer care. *Cancer Nurs*, 32(6), 493-502

Olsson C (2000) What are the special needs of chronically ill young people. *Australian Family Physician*, 29 (4), 299-300

Orr DP, Fineberg NS & Gray DL (1996) Glycemic control and transfer of health care among adolescents with insulin dependent diabetes mellitus. *Journal of Adolescent Health*, 18(1), 44-47

Orr DP, Pless IB, Satterwhite B & Wells SC (1984) Psychosocial implications of chronic illness in adolescence. *Journal of Pediatrics*, 104, 152-57

Østerlund CS, Dosa NP & Arnott Smith C (2005) Mother knows best: Medical record management for patients with spina bifida during the transition from pediatric to adult care, 580-4

Östlie I L, Dale Ö, & Möller A (2007) From childhood to adult life with juvenile idiopathic arthritis (JIA): A pilot study. *Disability & Rehabilitation*, 29(6), 445-52

Oswald DP, Bodurtha JN, Willis JH, et al (2007) Underinsurance and key health outcomes for children with special health care needs. *Pediatrics*, 119(2), e341-7

Ouellette M (2006) Going the distance: Serving the needs of older youth at scale. *New Dir Youth Development*, 111, 105-15, 11

Ouyang L, Grosse SD & Kenneson A (2008) Health care utilization and expenditures for children and young adults with muscular dystrophy in a privately insured population. *J Child Neurol*, 23(8), 883-8

Owen P & Beskine D (2008) Factors affecting transition of young people with diabetes. *Paediatr Nursing*, 20(7), 33-8

Pacaud D, McConnell B, Huot C, Aebi C & Yale J (1996) Transition from pediatric care to adult care for insulin-dependent diabetes patients. *Canadian Journal of Diabetes Care*, 20, 14-20

Pacaud D, Yale JF, Stephure D, Trussell R & Davies HD (2005) Problems in transition from pediatric care to adult care for individuals with diabetes. *Can J Diab*, 29(1), 13-18

PACER Center (1997) *Teens speak out: A survey of teens with chronic illness and disabilities in transition.* www.pacer.org

PACER Center (1993) *Speak Up for Health: Preparing Adolescents with Chronic Illness or Disability for Transition to Adult Health Care Services*, Minneapolis, MN: PACER Center

PACER Center and Minnesota Children with Special Health Needs. (1995) *Teens in Transition: What Teens are Saying*. Minneapolis, MN: Author

Padua L, Rendeli C, Rabini A, Gerardi E, Tonali P & Salvaggio E (2002) Health-related quality of life and disability in young patients with spina bifida. *Archives of Physical Medicine and Rehabilitation*, 83 (10), 1384-1388

Palisano RJ, Copeland WP & Galuppi BE (2007) Performance of physical activities by adolescents with cerebral palsy. *Phys Ther*, 87(1), 77-87

Palmer ML & Boisen LS (2002) Cystic fibrosis and the transition to adulthood. *Social Work in Health Care*, 36(1), 45-58

Palmer S, Mitchell A, Thompson K & Sexton M (2007) Unmet needs among adolescent cancer patients: A pilot study. *Palliat Support Care*, 5(2), 127-34

- Panitch HB & DeBrest C** (2003) Adolescence: Transitioning from pediatric to adult care. *Ventilator-Assisted Living*, 17 (2) 4-5
- Paone M, Whitehouse S & Stanford D** (1998) Challenges of transition: Coping with a chronic condition. *British Columbia Medical Journal*, 40(2), 73-75
- Paone MC, Wigle M & Saewyc E** (2006) The ON TRAC model for transitional care of adolescents. *Prog Transplant*, 16(4), 291-302
- Papagianni M & Stanhope R** (2003) How should we manage growth hormone deficiency in adolescence? Transition from paediatric to adult care. *J Pediatr Endocrinol Metab*, 16(1), 23-5
- Paradis AD, Reinherz HZ, Giaconia RM, & Fitzmaurice G** (2006) Major depression in the transition to adulthood: The impact of active and past depression on young adult functioning. *J Nerv Ment Dis*, 194 (5), 318-23
- Parish S & Huh J** (2006) Health care for women with disabilities: Population-based evidence of disparities. *Health & Social Work*, 31(1), 7-15
- Park MJ, Brindis CD, Chang F & Irwin Jr CE** (2008) A midcourse review of the Healthy People 2010: 21 Critical Health Objectives for Adolescents and Young Adults. *Journal of Adolescent Health*, 42(4), 329-334
- Park MJ & Irwin CE Jr** (2008) Youth with special health care needs: Facilitating a healthy transition to young adulthood. *Journal of Adolescent Health*, 43(1), 6-7
- Park MJ, Mulye TP, Adams SH, Brindis CD & Irwin, Jr CE** (2006) The health status of young adults in the United States. *Journal of Adolescent Health*, 39 (Sept, 3), 305-317
- Parfitt G** (2008) Proving young person's experience transition: Lessons from Wales. *Paediatr Nurs*, 20(9), 27-30
- Parker G & Hirst M** (1987) Continuity and change in medical care for young adults with disabilities. *Journal of the Royal College of Physicians of London*, 21(2), 129-133
- Parker HW** (2007) Transition and transfer of patients who have cystic fibrosis to adult care. *Clin Chest Med*, 28, 423-32
- Parslow R, Jorm A, Christensen H & Jacomb P** (2002) Factors associated with young adults' obtaining general practitioner services. *Aust Health Rev*, 25(6), 109-18
- Pascall G & Hendley N** (2004) Disability and transition to adulthood: The politics of parenting. *Critical Social Policy*, 24(2), 165-186
- Paterson B, Thorne S & Russell C** (2002) Disease-specific influences on meaning and significance in self-care decision-making in chronic illness. *Can J Nurs Res*, 34(3), 61-74
- Patrick DL** (1997) Rethinking prevention for people with disabilities. Part I: A conceptual model for promoting health. *American Journal of Health Promotion*, 11, 257-60
- Patton GC, Hetrick SE & McGorry P** (2007) Service responses for youth onset mental disorders. *Curr Opin Psychiatry*, 20(4), 319-24
- Patterson D & Lanier C** (1999) Adolescent health transitions: Focus group study of teens and young adults with special health care needs. *Family Community Health*, 22(2), 42-58
- Patterson JM & Blum RW** (1996) Risk and resilience among children and youth with disabilities. *Archives of Pediatric and Adolescent Medicine*, 150, 692-698
- Patterson JM & Blum RW** (1993) A conference on culture and chronic illness in childhood: Conference summary. *Pediatrics*, 91(5), 1025-10030
- Patterson J & Hovey D** (2000) Family-centered care for children with special health needs: Rhetoric or reality. *Family Systems & Health*, 18(2), 237-251
- Pavis S, Cunningham-Burley S & Amos A** (1998) Health related behavioural change in context: Young people in transition. *Social Science and Medicine*, 47, 1407-1418

- Percy-Smith B** (2007) 'You think you know? ... You have no idea': Youth participation in health policy development. *Health Educ Res*, 22(6), 879-94
- Pedreira CC, Hameed R, Kanumakala S, & Zacharin M** (2006) Health-care problems of Turner syndrome in the adult woman: A cross sectional study of a Victorian cohort and a case for transition. *Intern Med J*, 36(1) 54-7
- Perloff JK** (1991) Congenital heart disease in adults: A new cardiovascular sub-specialty. *Circulation*, 84, 1881-1890
- Perrin JM** (2002) Health services research for children with disabilities. *The Milbank Quarterly*, 80 (2), 303-324
- Perrin JM, Fluet CF, Honberg L, et al.** (2007) Benefits for employees with children with special needs: Findings from the Collaborative Employee Benefit Study. *Health Affairs*, 26(4), 1096-1103
- Perrin JM, Kuhlthau KA, Gortmaker SL, Beal AC & Ferris TG** (2002) Generalist and sub-specialist care for children with chronic conditions. *Ambulatory Pediatrics*, 2(6), 462-9
- Perrin JM & MacLean WE** (1988) Children with chronic illness: The prevention of dysfunction. *Pediatric Clinics of North America*, 35 (6), 1325-1337
- Perrin JM, Romm D, Bloom SR, Homer CJ, Kuhlthau KA, Cooley C, Duncan P, Roberts R, Sloyer P, Wells N & Newacheck P** (2007) A family-centered, community-based system of services for children and youth with special health care needs. *Arch Pediatr Adolesc Med*, 161(10), 933-6
- Peter NG, Forke CM, Ginsburg KR & Schwarz DF** (2009) Transition from pediatric to adult care: Internists' perspectives. *Pediatrics*, 123(2), 417-23
- Petersen LS, Mason T, Nelson AM, Fallon W & Gabriel SE** (1997) Psychosocial outcomes and health studies in adults who have had juvenile arthritis: A controlled population based study. *Arthritis Rheum*, 40, 2235-2240
- Peterson PM, Rauen KK, Brown J & Cole J** (1994) Spina bifida: The transition into adulthood begins in infancy. *Rehabilitation Nursing*, 19, 229-238
- Pfeffer PE, Pfeffer JM & Hodson ME** (2003) The psychosocial and psychiatric side of cystic fibrosis in adolescents and adults. *J Cyst Fibros*, 2(2), 61-8
- Pinzon JL, Jacobson K & Reiss J** (2004) Say goodbye and say hello: The transition from pediatric to adult gastroenterology. *Canadian Journal of Gastroenterology*, 18(12), 735-742
- Poa E** (2006) Trapped in transition: The complex young adult patient. *Bull Menninger Clin*, 70 (1), 29-52
- Pollock BH** (2007) Where adolescents and young adults with cancer receive their care: Does it matter? *J Clin Oncol*, 25(29), 4522-3; comment on 4610-5 and 4616-21
- Pollock N & Stewart D** (1990) A survey of activity patterns and vocational readiness of young adults with physical disabilities. *Canadian Journal of Rehabilitation*, 4(1), 17-26
- Pomery M, Iverson JM & Guillory JD** (2000) Health and Medical Issues for Transition-age Adolescents with Disabilities and/or Health Care Needs: A Guide for Teenagers and Their Families. Louisiana Healthy and Ready to Work. New Orleans, LA: Louisiana State University Health Science Center Human Development Center
- Poole DL** (1987) Competitive employment of persons with severe physical disabilities: A multivariate analysis. *Journal of Rehabilitation*, 53, 20-25
- Por J, Golberg B, Lennox V, Burr P, Barrow J & Dennard L** (2004) Transition of care: Health care professionals' view. *Journal of Nursing Management*, 12 (5), 354-361
- Porter S, Freeman L & Griffin LR** (2000) Transition Planning for Adolescents with Special Health Care Needs and Disabilities: A Guide for Health Care Providers. Boston, MA: Institute for Community Inclusion/UAP at Children's Hospital as part of the Massachusetts Initiative for Youth with Disabilities, a project of the Massachusetts Department of Public Health
- Pottick KJ, Bilder S, Vander Stoep A, Warner LA & Alvarez MF** (2008) US patterns of mental health service utilization for transition-age youth and young adults. *J Behav Health Serv Res*, 35(4), 373-89

- Power A** (2008) Caring for independent lives: Geographies of caring for young adults with intellectual disabilities. *Social Science and Medicine*, 67(5), 834-43
- Powers K, Hogansen J, Geenen S, Powers LE & Gil-Kashiwabara E** (2008) Gender matters in transition to adulthood: A survey study of adolescents with disabilities and their families. *Psychology in the Schools*, 45(4), 349-364
- Powers LE, Garner T, Valnes B, Squire P, Turner A, Couture T, et al** (2007) Building a successful adult life: Findings from youth-directed research. *Exceptionality. Special Issue: Self-Determination*, 15(1), 45-56
- Powers L, Singer G & Sowers J** (1996) *On the road to autonomy: Promoting self-competence in youth and young adults with disabilities*. Baltimore, MD: Paul H Brookes
- Powers LE, Sowers J & Stevens T** (1995) An exploratory randomized study of the impact of mentoring on the self-efficacy and community-based knowledge of adolescents with severe physical challenges. *Journal of Rehabilitation*, 61, 33-41
- Powers LE, Turner A & Ellison R** (2001) A multi-component intervention to promote adolescent self-determination. *Journal of Rehabilitation*, 67, 13-19
- Pratt HD** (2006) Office counseling for the adolescent. *Primary Care*, 33(2), 349-71
- Presler B** (1998) Care coordination for children with special health care needs. *Orthopaedic Nursing*, 17 (March-April Supplement), 45-51
- Pritchard C & Hean S** (2008) Suicide and undetermined deaths among youths and young adults in Latin America: Comparison with the 10 major developed countries--a source of hidden suicides? *Crisis*, 29(3), 145-53
- Pugeat M & Nicolino M** (2009) From paediatric to adult endocrinology care: the challenge of the transition period. *Pediatr Endocrinol Rev*, 6 Suppl 4:519-22
- Punch R, Hyde M & Creed PA** (2004) Issues in the school-to-work transition of hard of hearing adolescents. *Am Ann Deaf*, 149 (1), 28-38
- Putnam M, Geenen S, Powers LE, Saxton M, Finney S & Dautel P** (2003) Health and wellness: People with disabilities discuss barriers and facilitators to well being. *Journal of Rehabilitation*, 69 (1), 37 – 45
- Radovick S & DiVall S** (2007) Approach to the growth hormone-deficient child during transition to adulthood. *J Clin Endocrinol Metab*, 92(4), 1195-200
- Raghavan R, Shi P, Aarons GA, Roesch SC, McMillen JC** (2009) Health insurance discontinuities among adolescents leaving foster care. *J Adolesc Health*, 44(1), 41-7
- Ramini SK, Brown R & Buckner EB** (2008) Embracing changes: Adaptation by adolescents with cancer. *Pediatric Nursing*, 34(1), 72-9
- Rapanar C, Bartu A, & Lee AH** (2008) Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities*, 21(1), 34-47
- Rapaport R & Cook DM** (2006) Transition of childhood-onset growth hormone-deficient patients to adult healthcare. *Pediatr Endocrinol Rev*, 4 Suppl 1, 82-90
- Rapp CE Jr & Torres MM** (2000) The adult with cerebral palsy. *Arch Fam Med*, 9, 466-72
- Rasmussen B, Wellard S & Nankervis A** (2001) Consumer issues in navigating health care services for type I diabetes. *J Clin Nursing*, 628-34
- Reaman G, Bongiglio J & Krailo M** (1993) Cancer in adolescents and young adults. *Cancer*, 15, 3206-3209
- Rearick E** (2007) Enhancing success in transition service coordinators: Use of transformational leadership. *Professional Case Management*. 12(5), 283-287
- Reeve DK & Lincoln NB** (2002) Coping with the challenge of transition in older adolescents with epilepsy. *Seizure*, 33-9
- Regber S & Kelly KB** (2007) Missed opportunities-adolescents with a chronic condition (insulin-dependent diabetes mellitus) describe their cigarette-smoking trajectories and consider health risks. *Acta Paediatr*, 96(12), 1770-6

- Reid C** (2007) The transition from state care to adulthood: International examples of best practices. *New Dir Youth Dev*, 113 (Spring), 33-49, 10-1
- Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Sui SC & Webb CD** (2004) Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*, 133, e197-e205
- Reid GJ, Webb GD, McCrindle BW, Irvine MJ & Siu SC** (2008) Health behaviors among adolescents and young adults with congenital heart disease. *Congenit Heart Disease*, 3(1), 16-25
- Reinherz HZ, Paradis AD, Giaconia RM, Stashwick CK & Fitzmaurice G** (2003) Childhood and adolescent predictors of major depression in the transition to adulthood. *American Journal of Psychiatry*, 160(12), 2141-7
- Reiss J & Gibson R** (2002) Health care transition: Destinations unknown. *Pediatrics*, 110, 1307-1314
- Reiss JG, Gibson RW & Walker LR** (2005) Health care transition: Youth, family, and provider perspectives. *Pediatrics*, 115 (1), 112-120
- Remorino R & Taylor J** (2006) Smoothing things over: The transition from pediatric to adult care for kidney transplant recipients. *Prog Transplant*, 16(4), 303-8
- Repetto J B & Correa VI** (1996) Expanding views on transition. *Exceptional Children*, 62(6), 551-563
- Resnick MD, Bearman PS, Blum RW, Bauman KE, Harris KM & Jones J** (1997) Protecting adolescents from harm: Findings from the National Longitudinal Study on Adolescent Health. *JAMA*, 278, 823-832, 10
- Rettig P & Athreya BH** (1991) Adolescents with chronic disease: Transition to adult health care. *Arthritis Care and Research*, 4(4), 174-180
- Rew L** (2006) Sexual health promotion in adolescents with chronic health conditions. *Family and Community Health*, 29(1 Suppl), 61S-9S
- Richards M, Altisent C, Batorova A, Chambost H, Dolan G, de Moerloose P, Fraga M, Hermans C, Karafoulidou A, Klamroth R & Lassila R, Rothschild C** (2007) Should prophylaxis be used in adolescent and adult patients with severe haemophilia? An European survey of practice and outcome data. *Haemophilia*, 13(5), 473-9
- Richards M & Vostanis P** (2004) Interprofessional perspectives on transitional mental health services for young people aged 16-19 years. *Journal of Interprofessional Care*, 18(2), 115-128
- Richardson SA** (1989) Transition to adulthood. In Stein, REK, (ED), *Caring for Children with Chronic Illness: Issues and Strategies*. New York, NY: Springer Publishing Company
- Riley AW** (2004) Evidence that school-age children can self-report on their health. *Ambulatory Pediatrics*, 4, 371-376
- Rimmer JH** (1999) Health promotion for people with disabilities: The emerging paradigm shift from disability prevention to prevention of secondary conditions. *Physical Therapy*, 79, 495-502
- Rimmer JH, Rowland JL & Yamaki K** (2007) Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *Journal of Adolescent Health*, 41(3), 224-9
- Rinehart PM & Okinow NA** (1994) Health concerns for teens: A developmental perspective. *IMPACT Minneapolis: Institute on Community Integration, University of Minnesota*, 7(2), 2-3
- Ringeisen H, Casanueva CE, Urato M & Stambaugh LF** (2009) Mental health service use during the transition to adulthood for adolescents reported to the child welfare system. *Psychiatr Serv*, 60(8), 1084-91
- Rising JP, Colon-Hopkins C, Newman A, Kaiser E, Lange D, Thaw R, Katz MH & Fuentes-Afflick E** (2007) Healthy Young Adults: Description and use of an innovative health insurance program. *Journal of Adolescent Health*, 41 (4), 350-356
- Robertson L** (2006) When should young people with chronic rheumatic disease move from paediatric to adult-centred care. *Best Practi Res Clin Rheumatology*, 20 (2) 387-97

Robertson LM & Middleman A (1998) Knowledge of health insurance coverage by adolescents and young adults attending a hospital-based clinic. *Journal of Adolescent Health*, 22, 439-445

Robertson LP, McDonagh JE, Southwood TR & Shaw KL, British Society of Paediatric and Adolescent Rheumatology (2006) Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. *Ann Rheum Dis*, 65(1), 74-80

Robertson LP, McDonagh JE, Southwood TR & Shaw KL, (2006) Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. *British Medical Journal*, 65(1), 74

Rodriguez M & Labarta JI (2004) The need for specialized adolescent units. *J Pediatr Endocrinol Metab*, 17, Suppl 3, 481-4

Roebroek ME, Jahnsen R, Carona C, Kent RM & Chamberlain MA (2009) Adult outcomes and lifespan issues for people with childhood-onset physical disability. *Dev Med Child Neurol*, 51(8), 670-8

Roisman GI, Masten AS, Coatsworth JD & Tellegen A (2004) Salient and emerging developmental tasks in the transition to adulthood. *Child Development*, 75, 123-33

Rojewski J (1989) A rural based transition model for students with learning disabilities: A demonstration. *Journal of Learning Disabilities*, 22(10): 613-20

Rosen DS (2004) Transition of young people with respiratory diseases to adult health care. *Paediatr Respir Rev*, 5(2), 124-31

Rosen DS (1995) Between two worlds: Bridging the cultures of child health and adult medicine. *Journal of Adolescent Health*, 17, 10- 16

Rosen DS (1995) Cultures of care: Care of chronic conditions in pediatrics and internal medicine. *Journal of Adolescent Health*, 17, 10-16

Rosen DS (1994) Transition from pediatric to adult-oriented health care for the adolescent with chronic illness or disability. *Adolescent Medicine*, 5, 241-247

Rosen DS (1993) Transitions to adult health care for adolescents and young adults with cancer. *Cancer Supplement*, 71, 3411-3414

Rosen DS (1992) Growing up: Health care for adolescents and young adults with chronic conditions. *American Journal of Diseases of Children*, 146, 901-902

Rosen DS (1991) Growth and sexual maturation in adolescent with chronic disease, *Pediatrician*, 18, 105-120

Rosen DS, Blum RW, Britto M, Sawyer SM & Siegel DM (2003) Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 33(4), 309-11

Rosenbaum P & Stewart D (2007) Perspectives on transitions: Rethinking services for children and youth with developmental disabilities. *Arch Phys Med Rehabil*, 88(8), 1080-2

Rosenberg L, Blakeney P, Thomas CR, Holzer CE 3rd, Robert RS & Meyer WJ 3rd (2007) The importance of family environment for young adults burned during childhood. *Burns*, 33(5), 541-6

Rosenfeld RG (2002) Transitioning patients with childhood-onset growth hormone deficiency to treatment in adulthood. *J Pediatr Endocrinol Metab*, 1361-5

Rosenman KD, Hanna EA, Lyon-Callo SK & Wasilevich EA (2007) Investigating asthma deaths among children and young adults: Michigan Asthma Mortality Review. *Public Health Reports*, 122(3), 373-81

Ross HM & Fleck D (2007) Clinical considerations for allied professionals: Issues in transition to adult congenital heart disease programs. *Heart Rhythm*, 4(6), 811-3

Roush SE, Fresher-Samways K, Stolgitis J, Rabbitt J & Cardinal E (2007) Self- and caregiver-reported experiences of young adults with developmental disabilities. *J Soc Work Disabil Rehabil*, 6(4), 53-73

- Roux G, Sawin KJ, Bellin MH, Buran CF, Brei TJ & Fastenau, PS** (2007) The experience of being adolescent women with a disability. Part II: Peer relationships. *Rehabilitation Nursing*, 32(2), 112-9
- Rubin KJ** (2003) Transitioning the patient with Turner's syndrome from pediatric to adult care. *Pediatr Endocrinol Metab*, 16, Suppl 3, 651-9
- Rubin KR** (2008) Turner syndrome: Transition from pediatrics to adulthood. *Endocr Pract*, 14(6), 775-81
- Rurangirwa J, Braun KV, Schendel D & Yeargin-Allsopp M** (2006) Healthy behaviors and lifestyles in young adults with a history of developmental disabilities. *Res Dev Disabil*, 27(4):381-99
- Russell G** (2002) Asthma in the transition from childhood to adulthood. *Thorax*, 57(2), 96-7
- Russell M, Reinhold J & Maltby H** (1996) Transferring to adult health care: Experiences of adolescents with cystic fibrosis. *Journal of Pediatric Nursing*, 11(4), 262-268
- Rutkowski S & Riehle E** (2009) Access to employment and economic independence in cerebral palsy. *Phys Med Rehabil Clin N Am*, 20(3), 535-47
- Rutter M, Kim-Cohen J & Maughan B** (2006) Continuities and discontinuities in psychopathology between childhood and adult life. *J Child Psychol Psychiatry*, 47(3-4), 276-95
- Ryan S, Riley A, Kang M & Starfield B** (2001) The effect of regular source of care and health need on medical care use among rural adolescents. *Archives of Pediatric and Adolescent Medicine*, 155, 184-190
- Ryan SA, Millstein SG, Greene B & Irwin CE Jr** (1996) Utilization of ambulatory health services by urban adolescents. *Journal of Adolescent Health*, 18, 192-202
- Ryan SA, Millstein S, Kang M, Ensminger M, Starfield B & Irwin CE Jr** (1998) Adolescents' knowledge of their health insurance coverage. *Journal of Adolescent Health*, 22, 293-299
- Saba GW, Wong ST, Schillinger D, Fernandez A, Somkin CP, Wilson CC & Grumbach K** (2006) Shared decision making and the experience of partnership in primary care. *Ann Fam Med*, 4(1 Jan-Feb), 54-62
- Sadof MD & Nazarian BL** (2007) Caring for children who have special health-care needs: A practical guide for the primary care practitioner. *Pediatr Rev*, 28(7), e36-42
- Saetermoe CL, Farruggia SP & Lopez C** (1999) Differential parental communication with their adolescents who are disabled and their healthy siblings. *Journal of Adolescent Health*, 24, 427-432
- Saetersdal B** (1997) Forbidden suffering: The Pollyanna syndrome of the disabled and their families. *Family Process*, 36(4), 431-435
- Saggese G, Baroncelli GI, Vanacore T, Fiore L, Ruggieri S & Federico G** (2004) Indications and strategies for continuing GH treatment during transition from late adolescence to early adulthood in patients with GH deficiency: The impact on bone mass. *J Endocrinol Invest*, 27(6), 596-602
- Saigal S & Rosenbaum P** (2007) What matters in the long term: Reflections on the context of adult outcomes versus detailed measures in childhood. *Semin Fetal Neonatal Med*, 12(5), 415-22
- Saigal W, Stoskopf R, Streiner D, Boyle M, Pinelli J, Paneth N & Goddeeris J** (2006) Transition of extremely low-birth-weight infants from adolescence to young adulthood: Comparison with normal birth-weight controls. *JAMA*, 295 (6) 667-75 Comment in: 695-6; 295(22), 2603, author reply 2603.
- Salmi J, Huupponen H & Oksa H, et al.** (1986) Metabolic control in adolescent insulin-dependent diabetics referred from pediatric to adult clinic. *Annals of Clinical Research*, 18, 84-87
- Sanci LA, Coffey CMM, Veit FCM, Carr-Gregg M, Patton GC, Day N & Bowes G** (2000) Evaluation of the effectiveness of an educational intervention for general practitioners in adolescent health care: Randomised controlled trial. *British Medical Journal*, 320, 224-229
- Sandoval J, Bryan T & Burstein K** (2002) Getting youth up to PAR: Using participatory action research to increase self-determination skills. *Exceptional Parent*, 32(7), 36-38

- Sands D & Wehmeyer M** (1996) *Self determination across the lifespan: Independence and choice for people with disabilities*. Baltimore, MD: Paul H Brookes
- Sarmah A** (1999) Transitional care of young disabled people. *Archives of Disabled Children*, 81, 189
- Sat S, Sat B & Bowes G** (1997) Chronic Illness in adolescents: Transfer or transition to adult services? *J Paediatr Child Health*, 33, 88-90
- Savage MO & Besser GM** (1997) When and how to transfer patients from paediatric to adult endocrinologists: Experience from St Bartholomew's Hospital. London. *Acta Paediatr Sullo*, 423, 127-8
- Savage MO, Drake WM, Carrol PV & Monson JP** (2004) Transitional care of GH deficiency: When to stop GH therapy. *Eur J Endocrinol*, 151 (Aug), Suppl 2, S061-5
- Savage RC & Niemann GW** (2001) Transition services: Building a bridge between adolescence and young adulthood. *Brain Injury Source*, 5(2), 24, 27-30
- Sawin KJ, Bellin MH, Roux G, Buran CF & Brei TJ** (2009). The experience of self-management in adolescent women with spina bifida. *Rehabilitation Nursing*, 34(1), 26-38
- Sawin KJ, Buran CF & Brei TJ** (2007). Factors related to quality of life (HRQOL) in adolescents and young adults with Spina Bifida. *SCI Nursing*, 23(4)
- Sawin KJ, Cox AW, Metzger SG, Horsley JW, Harrigan MP, Deaton A & Thompson EC** (1999) Transition planning for youth with chronic conditions: An interdisciplinary process. *National Academies of Practice Forum*, 1 (3), 183-196
- Sawyer SM** (1998) Transition to adult health care. In GA Werther and TM Court (Eds) *Diabetes and the Adolescent*, 255-268
- Sawyer SM & Aroni RA** (2005) Self management in adolescents with chronic illness. What does it mean and how can it be achieved? *Medical Journal of Australia*, 183 (8), 405-409
- Sawyer SM, Blair S & Bowes G** (1997) Chronic illness in adolescents: Transfer or transition to adult services? *Journal of Paediatric and Child Health*, 33, 88-90
- Sawyer SM, Collins N, Bryan D, Brown D, Hope MA & Bowes G** (1998) Young people with Spina Bifida: Transfer from paediatric to adult health care. Preliminary report. *Journal of Paediatric and Child Health*, 34, 414-417
- Sawyer SM, Drew S, Yeo MS & Britto MT** (2007) Adolescents with a chronic condition: Challenges living, challenges treating. *Lancet*, 369, 1481-9
- Sawyer SM, Phelan PD & Bowes G** (1995) Reproductive health in young women with cystic fibrosis: Knowledge, behavior and attitudes. *Journal of Adolescent Health*, 17, 46-50
- Sawyer SM & Roberts KV** (1999) Sexual and reproductive health in young people with spina bifida. *Dev Med Child Neurol*, 41, 671-5
- Scabini E & Galimberti C** (1995) Adolescents and young adults: A transition in the family. *Journal of Adolescence*, 18, 593-606
- Scal P** (2002) Transition for youth with chronic conditions: Primary care physicians' approaches. *Pediatrics*, 110 (6), 1315-1321
- Scal P, Davern M, Ireland M & Park K** (2008) Transition to adulthood: Delays and unmet needs among adolescents and young adults with asthma. *J Pediatrics*, 152(4), 471-5, 475; comment 453-5
- Scal P, Evans T, Blozis S, Okinow N, & Blum R** (1999) Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *Journal of Adolescent Health*, 24, 259-264
- Scal P, Horvath K & Garwick A** (2009) Preparing for adulthood: Health care transition counseling for youth with arthritis. *Arthritis Rheum*, 15, 61(1), 52-7; comment in 15, 61(8), 1140-1

- Scal P & Ireland M** (2005) Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, 115, 1607-12
- Scal P & Town R** (2007) Losing insurance and using the emergency department: Critical effect of transition to adulthood for youth with chronic conditions. *Journal of Adolescent Health*, 40(2 Supplement), S4
- Scheer SD, Unger DG & Brown MB** (1996) Adolescents becoming adults: Attributes for adulthood. *Adolescence*, 31(121), 127-131
- Schidlow DV** (2002) Transition in cystic fibrosis: Much ado about nothing? A pediatrician's view. *Pediatr Pulmonol*, 33(5), 325-6
- Schidlow DV & Fiel SB** (1990) Life beyond pediatrics: Transition of chronically ill adolescents from pediatric to adult health care systems. *Medical Clinics of North America*, 74, 1113-1120
- Schilling EA, Aseltine RH & Gore S** (2008) The impact of cumulative childhood adversity on young adult mental health: Measures, models, and interpretations. *Social Science and Medicine*, 66(5), 1140-51
- Schilling EA, Aseltine RH Jr & Gore S** (2007) Adverse childhood experiences and mental health in young adults: A longitudinal survey. *BMC Public Health*, 7, 30
- Schopp LH, Sanford TC, Hagglund KJ, Gay JW & Coatney MA** (2002) Removing service barriers for women with physical disabilities: Promoting accessibility in the gynecologic care setting. *Journal of Midwifery & Women's Health*, 47(2), 74-79
- Schubiner H & Eggly S** (1995) Strategies for health education for adolescent patients: A preliminary investigation. *Journal of Adolescent Health*, 17, 3741
- Schulenberg JE, Bryant AL & O'Malley PM** (2004) Taking hold of some kind of life: How developmental tasks relate to trajectories of well-being during the transition to adulthood. *Developmental Psychopathology*, 16(4), 1119-40
- Schulenberg JE, Sameroff AJ & Cicchetti D** (2004) The transition to adulthood as a critical juncture in the course of psychopathology and mental health. *Developmental Psychopathology*, 16(4), 799-806
- Schultz A & Liptak G** (1998) Helping adolescents who have disabilities negotiate transitions to adulthood. *Issues in Comprehensive Pediatric Nursing*, 21, 187-201
- Schultz KA, Ness KK, Whitton J, Recklitis C, Zebrack B, Robison LL, Zeltzer L & Mertens AC** (2007) Behavioral and social outcomes in adolescent survivors of childhood cancer: A report from the childhood cancer survivor study. *J Clin Oncol*, 25(24), 3649-56
- Sears MR, Greene JM, Willan AR, Wiercek EM, Taylor DR, Flannery EM, Cowan JO, Herbison GP, Silva PA & Poulton R** (2003) A longitudinal, population-based cohort study of childhood asthma followed into adulthood. *New England Journal of Medicine*, 349 (15), 1414-1422
- Seekins T, Clay J & Raveslout C** (1994) A descriptive study of secondary conditions reported by a population of adults with physical disabilities served by three independent living centers in a rural state. *Journal of Rehabilitation*, 60, 47-51
- Settersten RA Jr, Frustenberg FF & Rumbaut RG** (2005) *On the Frontier of Adulthood: Theory, Research, and Public Policy*. Chicago: University of Chicago Press
- Shalet S** (2004) Stepping into adulthood: The transition period. *Hormone Research*, 62 (Suppl 4), 15-22
- Shapland C, Schoeller K & Smith J** (1993) *Speak Up for Health: Preparing Adolescents with Chronic Illness or Disabilities for Independence in Health Care: A Handbook for Parents*. PACER Center, Inc. Minneapolis, MN,
- Shattell MM, Bartlett R & Rowe T** (2008) "I have always felt different": The experience of attention-deficit/hyperactivity disorder in childhood. *J Pediatr Nursing*, 23(1), 49-57
- Shaw KL, Southwood TR & McDonagh JE** (2007) Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child Care Health Dev*, 33(4), 368-79
- Shaw KL, Southwood TR & McDonagh JE** (2007) Development and preliminary validation of the 'Mind the Gap' scale to assess satisfaction with transitional health care among adolescents with juvenile idiopathic arthritis. *Child Care Health Dev*, 33(4), 380-8

- Shaw KL, Southwood TR & McDonagh JE** (2004) Transitional care for adolescents with juvenile idiopathic arthritis: A Delphi study. *Rheumatology*, 43(8), 1000-1006
- Shaw KL, Southwood TR & McDonagh JE** (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: Results of a postal survey. *Rheumatology*, 43, 211-219
- Shaw KL, Southwood TR & McDonagh JE** (2004) User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology*, 43, 770-778
- Shroedel JG & Geyer PD** (2000) Long-term career attainments of deaf and hard of hearing college graduates: Results from a 15-year follow-up study. *American Annals of the Deaf*, 145(4), 303-314
- Shutz R** (1988) New directions and strategies in habilitation services: Toward meaningful employment outcomes. In L Heal, J Haney, & A Novak Amado (Eds.). *Integration of developmentally disabled individuals into the community Baltimore: Brookes*, pp. 193-209
- Shtayermman O** (2007) Peer victimization in adolescents and young adults diagnosed with Asperger's Syndrome: A link to depressive symptomatology, anxiety symptomatology and suicidal ideation. *Issues Compr Pediatr Nursing*, 30(3), 87-107
- Sices L, Harman JS & Kelleher KJ** (2007) Health-care use and expenditures for children in special education with special health-care needs: Is dual classification a marker for high use? *Public Health Reports*, 122(4), 531-40
- Siegel DM** (1987) Adolescents and chronic illness. *JAMA*, 257 (24), 3396-3399
- Silvers A** (1996) (In) equality, (ab) normality, and the Americans With Disabilities Act. *Journal of Medicine & Philosophy*, 21(2), 209-224
- Simeonsson RJ, McMillen JS & Huntington GS** (2002) Secondary conditions in children with disabilities: Spina Bifida as an example. *Ment Retard Dev Disabil Res Rev*, 8(3), 189-205
- Simon JL, Chesney RW, Alden ER, Mulvey HJ & Behrman RE** (2000) The future of pediatric education II: Organizing pediatric education to meet the needs of infants, children, adolescents, and young adults in the 21st century. *Pediatrics*, 105 (1 II), 162-212
- Simon TD, Lamb S, Murphy NA, Hom B, Walker ML & Clark EB** (2009) Who Will Care for Me Next? Transitioning to adulthood with hydrocephalus. *Pediatrics*, Oct 19. [Epub ahead of print]
- Singer GHS & Powers L** (1993) *Families, Disability, and Empowerment: Active Coping Skills and Strategies for Family Interventions*. Baltimore: Paul H. Brookes Publishing Co.
- Singh SP** (2009) Transition of care from child to adult mental health services: The great divide. *Curr Opin Psychiatry*, 22(4), 386-90
- Singh SP, Paul M, Ford T, Kramer T & Weaver T** (2008) Transitions of care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): A study of protocols in Greater London. *BMC Health Serv Research*, 8, 135
- Sinnema G** (1992) Youths with chronic illness and disability on their way to social and economic participation: A health-care perspective. *Journal of Adolescent Health*, 13 (5), 369-371
- Slap G** (1992) Youth in transition to adult health care. In McAnarney, ER, Kreipe, RE, Orr DP, & Comerci GD (Eds.). *Textbook of Adolescent Medicine*. Philadelphia, PA: WB Saunders, 245-248
- Smith DE** (1994) Health care of the disabled adolescent. *Current Opinion in Pediatrics*, 6, 397-401
- Smith PE, Myson V & Gibbon F** (2002) A teenager epilepsy clinic: Observational study. *Eur J Neurol*, 373-6
- Smith S, Davies S, Wright D, Chapman C & Whiteson MBE** (2007) The experiences of teenagers and young adults with cancer-Results of 2004 conference survey. *European Journal of Oncology Nursing*, 11 (4), 362-368
- Smith V** (1997) Primary care for persons with disabilities: Public policy perspective. *American Journal of Physical Medicine and Rehabilitation*, S14-16

- Smull M & Bellamy G** (1991) Community services for adults with disabilities: Policy challenges in the emerging support paradigm In L. Meyer, C. Peck, & L. Brown (Eds.) *Critical issues in the lives of people with severe disabilities*. Baltimore: Paul H. Brookes Publishing Co., 527-536
- Sneed RC, May WL & Stencil C** (2004) Policy versus practice: comparison of prescribing therapy and durable medical equipment in medical and educational settings. *Pediatrics*, 114(5), e612-25
- Snowden LR, Cuellar,AE & Libby AM.** (2003) Minority youth in foster care: Managed care and access to mental health treatment. *Med Care*, 41(2), 264-74
- Soanes C & Timmons SJ** (2004) Improving transition: A qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *Child Health Care*, 9(2), 102-12
- Somerville J** (2002) Grown-up congenital heart (GUCH) disease: Current needs and provision of service for adolescents and adults with congenital heart disease in the UK. *Heart*, 88 (SUPPL. 1), i1-i14
- Somerville J** (1997) Management of adults with congenital heart disease: An increasing problem. *Annu Rev Med*, 48, 283-293
- Somerville J** (1997) Near misses and disasters in the treatment of grown-up congenital heart patients. *J R Soc Med*, 90 (3), 124-127
- Sood MR & Rudolph CD** (2007) Gastrointestinal motility disorders in adolescent patients: Transitioning to adult care. *Gastroenterol Clin North America*, 36(3), 749-63, xi
- Southerland D, Casanueva CE & Ringeisen H** (2009) Young adult outcomes and mental health problems among transition age youth investigated for maltreatment during adolescence. *Children and Youth Services Review*, 31 (9), 947-956
- Sowers J** (1991) Employment for persons with physical disabilities and related technology. *Journal of Vocational Rehabilitation*, 55-64
- Sox CM, Swartz K, Burstin HR & Brennan TA** (1998) Insurance or a regular physician: Which is the most powerful predictor of health care? *American Journal of Public Health*, 88, 364-370
- Sparacino PSA, Tong EM, Messias DKH, Foote D, Chesla CA & Gilliss CL** (1997) The dilemmas of parents of adolescents and young adults with congenital heart disease. *Heart & Lung: Journal of Acute and Critical Care*, 26, 187-195
- Spencer CH, Fife RZ & Rabinovich CE** (1995) The school experience of children with arthritis: Coping in the 90's and transition to adulthood. *Pediatric Clinics of North America*, 42, 1285-1298
- Spencer JE, Emery LJ & Schneck CM** (2003) Occupational therapy in transitioning adolescents to post-secondary activities. *Am J Occup Ther*, 57(4), 435-41
- Srof BJ & Velsor-Friedrich B** (2006) Health promotion in adolescents: A review of Pender's Health Promotion Model. *Nurs Sci Q*, 19(4 Oct), 366-73
- Stabile L, Rosser L, Porterfield KM, McCauley S, Levenson C, Haglund J & Christman K** (2005) Transfer versus transition: Success in pediatric transplantation brings the welcome challenge of transition. *Prog Transplant*, 15(4), 363-70
- Stacey WA** (2001) The stress of progression from school to work for adolescents with learning disabilities: What about life progress? *Work*, 17, 175-181
- Stam H, Hartman EE, Deurloo JA, Groothoff J & Grootenhuis MA** (2006) Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *Journal of Adolescent Health*, 39, 4-13
- Stanley N, Manthorpe J & Gillespie L** (2008) Family physicians' interventions with young people in distress and their parents: Managing confidentiality and levels of engagement. *Acad Psychiatry*, 32(2), 92-7
- Steinbeck KS, Brodie L & Towns SJ** (2008) Transition in chronic illness: Who is going where? *J Paediatrics and Child Health*, 44(9), 478-82; comment 475-7
- Steinbeck KS, Brodie L & Towns SJ** (2007) Transition care for young people with chronic illness. *Int J Adolesc Med Health*, 19(3), 295-303

- Steinberg L** (2000) The family at adolescence: Transition and transformation. *Journal of Adolescent Health*, 27, 170-178
- Steinkamp G, Ullrich G, Muller C, Fabel H & von der Hardt H** (2001) Transition of adult patients with cystic fibrosis from paediatric to adult care--the patients' perspective before and after start-up of an adult clinic. *Eur J Med Res*, 28, 6(2), 85-92
- Stellman-Ward G, Bannister CM & Lewis M** (1993) Assessing the needs of the adult with spina bifida. *European Journal of Pediatric Surgery*, 3, 14-16
- Stephens DL, Collins MD & Dodder RA (2005)** A longitudinal study of employment and skill acquisition among individuals with developmental disabilities. *Res Dev Disabil*, 26(5), 469-86
- Stern HP, Garg A & Stern TP** (2002) When children with attention-deficit/hyperactivity disorder become adults. *Southern Medical Journal*, 95, 985-991
- Stevens SE, Steele CA, Jutai JW, Kalnins IV, Bortolussi JA & Biggar WD** (1996) Adolescents with physical disabilities: Some psychosocial aspects of health. *Journal of Adolescent Health*, 19, 157-164
- Stevenson CJ, Pharoah POD & Stevenson R** (1997) Cerebral palsy—the transition from youth to adulthood. *Developmental Medicine & Child Neurology*, 39, 226-342
- Stewart, D** (2009) Transition to adult services for young people with disabilities: Current evidence to guide future research. *Dev Med Child Neurol*, 51(Oct); Suppl 4, 169-73
- Stewart D** (2006) Evidence to support a positive transition into adulthood for youth with disabilities. *Physical and Occupational Therapy in Pediatrics*, 26(4), 1-4
- Stewart D, Stavness C, King G, Antle B, Law M** (2006) A critical appraisal of literature reviews about the transition to adulthood for youth with disabilities. *Physical and Occupational Therapy in Pediatrics*, 26(4), 5-24
- Stewart DA, Law MC, Rosenbaum P & Willms DG** (2001) A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical and Occupational Therapy in Pediatrics*, 21(4), 3-21
- Stineman RM, Morningstar ME, Bishop B & Turnbull HR** (1993) Role of families in transition planning for young adults with disabilities: Toward a method of person-centered planning. *Journal of Vocational Rehabilitation*, 3(2), 52-61
- Stoep A V, Beresford SAA, Weiss N, McKnight B, Cauce AM & Cohen P** (2000) Community-based study of the transition to adulthood for adolescents with psychiatric disorder. *American Journal of Epidemiology*, 152(4), 352-362
- Stower S** (1998) A role in smooth transitions. *Paediatric Nursing*, 10(5), 6
- Straatman LP** (2000) Transition to adult care in adolescents with cardiac disease. *Perspectives in Cardiology*, 16, 30-37
- Strax TE** (1991) The psychological issues faced by adolescents and young adults with disabilities. *Pediatric Annuals*, 20, 507-511
- Strickland B, McPherson M & Weissman G** (2004) Access to the medical home: Results of the National Survey of Children with Special Health Care Needs. *Pediatrics*, 113, 1485-1498
- Ströhle A, Höfler M, Pfister H, Müller AG, Hoyer J, Wittchen HU & Lieb R** (2007) Physical activity and prevalence and incidence of mental disorders in adolescents and young adults. *Psychol Med*, 37(11), 1657-66
- Sturrock T, Masterson L & Steinbeck K** (2007) Adolescent appropriate care in an adult hospital: The use of a youth care plan. *Aust J Adv Nursing*, 24(3), 49-53
- Suris JC** (1995) Global trends of young people with chronic and disabling conditions. *Journal of Adolescent Health*, 17(1), 17-22
- Suris JC, Michaud PA & Viner R** (2004) The adolescent with a chronic condition. Part I: Developmental issues. *Arch Dis Child*, 89, 938-942
- Suris JC, Parera N & Puig C** (1996) Chronic illness and emotional distress in adolescence. *J Adolesc Health*, 19, 153-156

- Suris JC, Resnick M & Cassuto N** (1996) Sexual behavior of adolescents with chronic disease and disability. *J Adolesc Health*, 19, 124-131
- Swanton R, Collin P, Burns J & Sorensen I** (2007) Engaging, understanding and including young people in the provision of mental health services. *Int J Adolesc Med Health*, 19(3), 325-32
- Szymanski EM** (1994) Transition: Life-span and life-space considerations for empowerment. *Exceptional Children*, 60(5), 402-410
- Taggart L & McMullan P** (2007) An exploratory study of teachers' knowledge about the symptoms of depression in young people with and without intellectual disabilities. *J Intellect Disabil*, 11(2), 183-95
- Tan MJ & Klimach VJ** (2004) Portfolio of health advice for young people with disabilities transferring to adult care. *Child Care Health Dev*, 30, 291-6
- Tandon SD, Marshall B, Templeman AJ & Sonenstein FL** (2008) Health access and status of adolescents and young adults using youth employment and training programs in an urban environment. *Journal of Adolescent Health*, 43(1), 30-7
- Taylor HC, Stuttaford MC, Broad B & Vostanis P** (2007) Listening to service users: Young homeless people's experiences of a new mental health service. *J Child Health Care*, 11(3), 221-30
- Taylor L, Tsang A & Drabble A** (2006) Transition of transplant patients with cystic fibrosis to adult care: Today's challenges. *Prog Transplant*, 16(4), 329-34
- Telfair J** (1994) Factors in the long term adjustment of children and adolescents with sickle cell disease: Conceptualizations and review of the literature. *Journal Health and Social Policy*, 5(3/4), 69-96
- Telfair J, Alexander LR, Loosier PS, Alleman-Velez PL & Simmons J** (2004) Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved*, 15(3), 443-61
- Telfair J, Ehiri JE, Loosier PS & Baskin ML** (2004) Transition to adult care for adolescents with sickle cell disease: Results of a national survey. *International Journal of Adolescent Medicine and Health*, 16, 47-64
- Telfair J, Myers J & Drezner S** (1994) Transfer as a component of the transition of adolescents with sickle cell disease to adult care: Adolescent, adult, and parent perspectives. *Journal of Adolescent Health*, 15 (7), 558-565
- Tervo RC, Symons F, Stout J & Novacheck T** (2006) Parental report of pain and associated limitations in ambulatory children with cerebral palsy. *Arch Phys Med Rehabil*, 87(7), 928-34
- Thomas DM, Seymour JF, O'Brien TO, Sawyer, M & Ashley DM** (2006) Adolescent and young adult cancer: A revolution in evolution? *Internal Medicine Journal*, 36, 302-307
- Thompson CE** (1990) Transition of the disabled adolescent to adulthood. *Pediatrician*, 17, 308-313
- Thompson K, Palmer S & Dyson G** (2009) Adolescents & young adults: Issues in transition from active therapy into follow-up care. *Eur J Oncol Nurs*, 13(3), 207-12
- Thorin E J & Irvin LK** (1992) Family stress associated with transition to adulthood of young-people with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 17(1), 31-39
- Thorpe CT, Lewis MA & Sterba KR** (2008) Reactions to health-related social control in young adults with type 1 diabetes. *J Behav Med*, 31(2), 93-103
- Tielen M, van Staa AL, Jedeloo S, van Exel NJ & Weimar W** (2008) Q-methodology to identify young adult renal transplant recipients at risk for nonadherence. *Transplantation*, 85(5), 700-6
- Timmons JC, Whitney-Thomas J, McIntyre JP, Butterworth J & Allen D** (2004) Managing service delivery systems and the role of parents during their children's transitions. *Journal of Rehabilitation*, 70 (2), 19-26
- Tobaiasen J & Hiebert J** (1993) Clefting and psychological adjustment: Influence of facial aesthetics. *Clinics in Plastic Surgery*, 20 (4), 623-631
- Todis B & Glang A** (2008) Redefining success: Results of a qualitative study of postsecondary transition outcomes for youth with traumatic brain injury. *J Head Trauma Rehabil*, 23(4), 252-63

Tong EM & Kools S (2004) Health care transitions for adolescents with congenital heart disease: Patient and family perspectives. *Nursing Clinics of North America*, 39(4), 727-40

Towns SJ, Sawyer SM, Stephens L, Clarke SD & Bennett DL (2007) Hospital based care of young people in Australia. *Int J Adolesc Med Health*, 19(3), 317-23

Tracy J & Henderson D (2004) Children and adolescents with developmental disabilities. The GP's role. *Aust Fam Physician*, 33(8), 591-7

Trainor AA (2005) Self-determination perceptions and behaviors of diverse students with LD during the transition planning process. *Journal of Learning Disabilities*, 38(3), 233-49

Tremblay T, Smith J, Xie H & Drake RE (2006) Effect of benefits counseling services on employment outcomes for people with psychiatric disabilities. *Psychiatr Serv*, 57(6), 816-21

Trupin EW, Turner AP, Stewart D & Wood P (2004) Transition planning and recidivism among mentally ill juvenile offenders. *Behav Sci Law*, 22, 599-610

Tsamasiros J & Bartsocas CS (2002) Transition of the adolescent from the children's to the adults' diabetes clinic. *J Pediatr Endocrinol Metab*, 15(4 Apr), 363-7

Tuchman LK, Slap GB & Britto MT (2008) Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev*, 34(5), 557-63

Tucker LB & Cabral DA (2007) Transition of the adolescent patient with rheumatic disease: Issues to consider. *Rheum Dis Clin North America*, 33(3), 661-72. Republished from *Pediatr Clin North America*, 2005, 52(2), 641-52, viii

Tuffrey C & Pearce AJ (2003) Transition from paediatric to adult medical services for young people with chronic neurological problems. *Neurol Neurosurg Psychiatry*, 74(8), 1011-3

Turchi RM, Gatto M & Antonelli R (2007) Children and youth with special healthcare needs: There is no place like (a medical) home. *Curr Opin Pediatr*, 19, 503-8

Turk MA, Geremski CA, Rosenbaum PF, Weber RJ (1997) The health status of women with cerebral palsy. *Arch Phys Med Rehabil*, 78(12 Suppl 5), S10-7

Turkel S & Pao M (2007) Late consequences of chronic pediatric illness. *Psychiatr Clin North America*, 30(4), 819-35

Turnbull AP & Turnbull HR (1985) Developing independence. *Journal of Adolescent Health Care*, 6, 108-119

Turner RJ, Taylor J & Van Gundy K (2004) Personal resources and depression in the transition to adulthood: Ethnic comparisons. *Journal of Health and Social Behavior*, 45(1), 34-52

Turner-Henson A, Holaday B, Corser N, Ogletree G & Swan J (1994) The experiences of discrimination: Challenges for chronically ill children. *Pediatric Nursing*, 20 (6), 571-577

Tweddle A (2007) Youth leaving care: How do they fare? *New Dir Youth Dev*, 113 (Spring), 15-31, 9-10

Umbarger GT, Turnbull HR, Morningstar ME, Reichard A & Moberly RL (2001) Funding challenges during transition to adulthood for young adults who use medical technology. *Journal of Developmental and Physical Disabilities*, 13(2), 141-167

Undén AL, Elofsson S, Andréasson A, Hillered E, Eriksson I & Brismar K (2008) Gender differences in self-rated health, quality of life, quality of care, and metabolic control in patients with diabetes. *Gend Medicine*, 5(2), 162-80

Uphold CR & Graham MV (1993) Schools as centers for collaborative services for families: A vision for change. *Nursing Outlook*, 41, 204-211

US Department of Health and Human Services (2005) The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. US Department of Health and Human Services, Office of the Surgeon General. <http://www.surgeongeneral.gov/library/disabilities/index.html>

US Department of Health and Human Services (2002) Surgeon General's Conference on Health Disparities and Mental Retardation. Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation. <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?call=bv.View..ShowSection&rid=hstat5.chapter.3384>

US Department of Health and Human Services (2001) Delivering on the Promise: Preliminary Report of Federal Agencies' Actions to Eliminate Barriers and Promote Community Integration. This and other New Freedom Initiative Progress Reports available at: <http://www.ancor.org/issues/olmstead/index.html>

Valentino LA, Santagostino E, Blanchette V & van den Berg M (2006) Managing the pediatric patient and the adolescent/adult transition. *Semin Thromb Hemost*, 32 (2 Jun Suppl), 28-31

Valenzuela JM, Buchanan CL, Radcliffe J, Ambrose C, Hawkins LA, Tanney M & Rudy BJ (2009) Transition to adult services among behaviorally infected adolescents with HIV--A qualitative study. *J Pediatr Psychol*, Jun 19. [Epub ahead of print]

Vanbergeijk E, Klin A & Volkmar F (2008) Supporting more able students on the autism spectrum: College and beyond. *J Autism Dev Disord*, 38(7), 1359-70

van der Dussen L, Nieuwstraten W, Roebroek M & Stam HJ (2001) Functional level of young adults with cerebral palsy. *Clin Rehabil*, 15, 84-91

van der Sluijs Veer L, Kempers MJ, Last BF, Vulsma T & Grootenhuis MA (2008) Quality of life, developmental milestones, and self-esteem of young adults with congenital hypothyroidism diagnosed by neonatal screening. *J Clin Endocrinol Metab*, 93(7), 2654-61

Vander Stoep A, Beresford SAA, Weiss NS, McKnight B, Cauce AM & Cohen P (2000) Community-based study of the transition to adulthood for adolescents with psychiatric disorder. *American Journal of Epidemiology*, 152, 352-362

Vander Stoep A, Weiss NS, McKnight B, Beresford SAA & Cohen P (2002) Which measure of adolescent psychiatric disorder—diagnosis, number of symptoms, or adaptive functioning—best predicts adverse young adult outcomes? *Journal of Epidemiology and Community Health*, 56(1), 56-65

Van Deyk K, Moons P, Gewillig M & Budts W (2004) Educational and behavioral issues in transitioning from pediatric cardiology to adult-centered health care. *Nursing Clinics of North America*, 39(4), 755-68

van Dyck PC, Kogan MD, McPherson MG, Weissman,GR & Newacheck PW (2004) Prevalence and characteristics of children with special health care needs. *Archives of Pediatric and Adolescent Medicine*, 158, 884-890

van Dyck PC, McPherson M, Strickland BB, Nesseler K, Blumberg SJ, Cynamon ML & Newacheck PW (2002) The National Survey of Children with Special Health Care Needs. *Ambulatory Pediatrics*, 2, 29-37

Vanelli M, Caronna S, Adinolfi B, Chiari G, Gugliotta M & Arsenio L (2004) Effectiveness of an uninterrupted procedure to transfer adolescents with Type 1 diabetes from the paediatric to the adult clinic held in the same hospital: Eight-year experience with the Parma protocol. *Diabetes Nutr Metab*, 17(5), 304-8

Vanheusden K, Mulder CL, van der Ende J, van Lenthe FJ, Mackenbach JP & Verhulst FC (2008) Young adults face major barriers to seeking help from mental health services. *Patient Educ Couns*, 73(1), 97-104

Vanheusden K, van der Ende J, Mulder CL, van Lenthe FJ, Verhulst FC & Mackenbach JP (2008) The use of mental health services among young adults with emotional and behavioural problems: Equal use for equal needs? *Soc Psychiatry Psychiatr Epidemiol*, 43(10), 808-15

Van Naarden Braun K, Yeargin-Aillsopp M & Lollar D (2006) A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. *Disabil Rehabil*, 15, 28(15 Aug), 915-28

Van Naarden Braun K, Yeargin-Aillsopp M & Lolla, D (2006) Factors associated with leisure activity among young adults with developmental disabilities. *Res Dev Disabil*, 27(5), 567-83

Van Wallegghem N, Macdonald CA & Dean HJ (2008) Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. *Diabetes Care*, 31(8), 1529-30

Van Wallegghem N, MacDonald CA & Dean HJ (2006) Building connections for young adults with type 1 diabetes mellitus in Manitoba: Feasibility and acceptability of a transition initiative. *Chronic Dis Can*, 27(3), 130-4

Verheugt CL, Uiterwaal CS, Grobbee DE & Mulder BJ (2008) Long-term prognosis of congenital heart defects: A systematic review. *International Journal of Cardiology*, 131 (1), 25-32

- Verlinde F, Massa G, Lagrou K, Froidecoeur C, Bourguignon JP, Craen M, De Schepper J, Du Caju M, Heinrichs C, Francois I & Maes M; Belgian Study Group of Paediatric Endocrinology** (2004) Health and psychosocial status of patients with Turner Syndrome after transition to adulthood: The Belgian experience. *Hormone Research*, 62(4), 161-7
- Vincentiis S, Clovis S, Saito M, et al** (2006) Sexuality in female adolescents with epilepsy: Unmet counseling needs. *Epilepsia*, 47:S4
- Viner R** (2003) Bridging the gaps: Transition for young people with cancer. *European Journal of Cancer*, 39(18), 2684-7
- Viner R** (2001) Barriers and good practice in transition from paediatric to adult care. *Journal of the Royal Society of Medicine*, 94 (Supplement 40), 2-4
- Viner R** (2000) Effective transition from paediatric to adult services. *Hosp Med*, 61, 341-343
- Viner RM** (2008) Transition of care from paediatric to adult services: One part of improved health services for adolescents. *Arch Dis Child*, 93(2), 160-3
- Viner RM** (2007) Do adolescent inpatient wards make a difference? Findings from a national young patient survey. *Pediatrics*, 120(4), 749-55
- Viner RM** (1999) Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood*, 81(3), 271-75
- Vingilis E, Wade T & Seeley J** (2007) Predictors of adolescent health care utilization. *Journal of Adolescence*, 30 (5), 773-800
- Vingilis E, Wade TJ & Seeley J** (2002) Predictors of adolescent self-rated health: Analysis of the National Population Health Survey. *Canadian Journal of Public Health*, 93 (3), 193-197
- Visentin K, Koch T & Kralik D** (2006) Adolescents with Type 1 Diabetes: Transition between diabetes services. *Journal of Clinical Nursing*, 15, (6 Jun), 761-9
- Visser-van Balen H, Geenen R, Kamp GA, Huisman J, Wit JM & Sinnema G** (2007) Long-term psychosocial consequences of hormone treatment for short stature. *Acta Paediatr*, 96(5), 715-9
- Vogel LC, Anderson CJ & Willis KM** (2004) Transition to adulthood: Perception of adults with physical disabilities and their parents. *Developmental Medicine and Child Neurology*, 46, 27
- Vogel LC, Klaas SJ, Lubicky JP, & Anderson CJ** (1998) Long-term outcomes and life satisfaction of adults who had pediatric spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, 79, 1496-1503
- Volta C, Luppino T, Street ME & Bernasconi S** (2003) Transition from pediatric to adult care of children with chronic endocrine diseases: A survey on the current modalities in Italy. *Journal of Endocrinological Investigation*, 26, 157-162
- Von Korff M, Grumen J, Schaefer L, et al** (1997) Collaboration management of chronic illness. *Annals of Internal Medicine*, 127, 1097-1102
- Vostanis P** (2005) Patients as parents and young people approaching adulthood: How should we manage the interface between mental health services for young people and adults? *Curr Opin Psychiatry*, 18, (4 Jul), 449-54
- Wagner MM** (1995) Outcomes for youths with serious emotional disturbance in secondary school and early adulthood, in *The Future of Children: Critical Issues for Children and Youths*, Vol 5. Princeton, NJ, Princeton University, Woodrow Wilson School of Public and International Affairs, and Brookings Institution
- Wagner M & Davis M** (2006) How are we preparing students with emotional disturbances for the transition to young adulthood? Findings from the national longitudinal transition study - 2. *Journal of Emotional and Behavioral Disorders*, 14(2), 86-98
- Wagner M, Kutash K, Duchnowski AJ & Epstein MH** (2005) The special education elementary longitudinal study and the national longitudinal transition study: Study designs and implications for children and youth with emotional disturbance. *Journal of Emotional and Behavioral Disorders*, 13(1), 25-42
- Waite E & Laraque D** (2006) Pediatric organ transplant patients and long-term care: A review. *Mt Sinai J Med*, 73(8), 1148-55

- Waldinger RJ, Diguier L, Guastella F, Lefebvre R, Allen JP, Luborsky L & Hauser ST** (2002) The same old song? Stability and change in relationship schemas from adolescence to young adulthood. *J Youth Adolesc*, 31, (1 Feb), 17-29
- Walker Z & Townsend J** (1999) The role of general practice in promoting teenage health: A review of the literature. *Family Practice*, 16 (2), 164-172
- Walker Z, Townsend J, Oakley L, Donovan C, Smith H & Hurst Z** (2002) Health promotion for adolescents in primary care: Randomised controlled trial. *British Medical Journal*, 325, 529-534
- Wallis C** (2007) Transition of care in children with chronic disease. *BMJ*, 334(7606), 1231-2
- Warnell P** (1998) Transition experience of epilepsy patients/families: Results of a telephone survey. *AXON*, 31-33
- Watson AR** (2005) Problems and pitfalls of transition from paediatric to adult renal care. *Pediatr Nephrolol*, 20 (2), 113-7
- Watson AR** (2000) Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr Nephrol*, 14 (6), 469-472
- Watson AR & Shooter M** (1996) Transitioning adolescents from pediatric to adult dialysis units. *Advances in Peritoneal Dialysis*, 12, 176-178
- Watson L** (2006) Too old at 18: A parent's view of transition. *Paediatric Nursing*, 18(7 Sep), 25
- Webb AK, Jones AW, & Dodd ME** (2001) Transition from paediatric to adult care: Problems that arise in the adult cystic fibrosis clinic. *Journal of the Royal Society of Medicine*, 94 (Suppl 40), 8-11
- Weekes D** (1995) Adolescents growing up chronically ill: A life-span developmental view. *Family and Community Health*, 17, 22-34
- Wehman P** (1996) *Life beyond the classroom. Transition strategies for young people with disabilities* (2nd ed.). Baltimore: Paul H. Brookes
- Wehman P, Kregel J, & Barcus J** (1985) From school to work: A vocational transition model for handicapped students. *Exceptional Children*, 52 (1), 2537
- Wehman PH, Revell WG, Kregel J, Kreutzer JS, Callahan M & Banks D** (1991) Supported employment: An alternative model for vocational rehabilitation of persons with severe neurologic, psychiatric, or physical disability. *Archives of Physical Medical Rehabilitation*, 72, 101-105
- Wehmeyer M** (1997) Self-determination as an educational outcome: A definitional framework and implications for intervention. *Journal of Development and Physical Disabilities*, 9 (3)
- Wehmeyer ML & Gragoudas S** (2004) Centers for independent living and transition-aged youth. *Journal of Vocational Rehabilitation*, 17, 1-6.
- Wehmeyer ML & Gragoudas S** (2004) Centers for independent living and transition-age youth: Empowerment and self-determination. *Journal of Rehabilitation*, 20, 53-58
- Wehmeyer ML & Palmer SB** (2003) Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities*, 38, 131-144.
- Wehmeyer ML & Schwartz M** (1998) The relationship between self-determination, quality of life, and life satisfaction for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33, 3-12
- Wehmeyer M & Schwartz M** (1997) Self-determination and positive adult outcomes: A follow- up study of youth with mental retardation or learning disabilities. *Exceptional Children*, 63 (2), 245-255
- Weist MD, Proescher E, Prodent C, Ambrose MG & Waxman RP** (2001) Mental health, health, and education staff working together in schools. *Child & Adolescent Psychiatric Clinics of North America*, 10 (1), 33-44

Weller WE, Minkovitz CS & Anderson GF (2003) Utilization of medical and health-related services among school-age children and adolescents with special health care needs (1994 National Health Interview Survey on Disability (NHIS-D)) Baseline Data. *Pediatrics*, 112 (3), 593-603

Wells JE, Horwood LJ & Fergusson DM (2007) Reasons why young adults do or do not seek help for alcohol problems. *Aust N Z J Psychiatry*, 41(12), 1005-12

Welner SL (1993) Gynecologic care of the disabled woman. *Contemporary OB/GYN*, 8 (1), 55-67

Welner SL, Foley CC, Nosek MA & Holmes A (1999) Practical considerations in the performance of physical examinations on women with disabilities. *Obstetrical and Gynecological Survey*, 54(7), 457-62

Wenzel SL, Hambarsoomian K, D'Amico EJ, Ellison M & Tucker JS (2006) Victimization and health among indigent young women in the transition to adulthood: A portrait of need. *J Adolesc Health*, 38 (5 May), 536-43

Werner P (1997) Primary care for persons with disabilities: A family practice perspective. *American Journal of Physical Medicine & Rehabilitation*, 76, 521-524

Westbrook LE, Silver EJ & Stein REK (1998) Implications of estimates of disability in children: A comparison of definitional components. *Pediatrics*, 101, 1025-1030

Westmorland MG, Williams R, Strong & Arnold E (2002) Perspectives on work (re)entry for persons with disabilities: Implications for clinicians. *Work*, 18, 29-40

Westwood A, Henley LD & Willcox P (1999) Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *Journal of Paediatric and Child Health*, 35, 442-445

Whelan J (2003) Where should teenagers with cancer be treated? *Eur J Cancer*, 39(18 Dec), 2573-8

While A, Forbes A, Ullman R, Lewis S, Mathes L & Griffiths P (2004) Good practices that address continuity during transition from child to adult care: Synthesis of the evidence. *Child Care Health Dev*, 30 (5), 439-52

While AE & Mullen J (2004) Living with sickle cell disease: The perspective of young people. *British Journal of Nursing*, 13(6), 320-5

White PH (2002) Transition: A future promise for children and adolescents with special health care needs and disabilities. *Rheum Dis Clin North America*, 28(3), 687-703, viii

White PH (2002) Access to health care: Health insurance considerations for young adults with special health care needs/disabilities. *Pediatrics*, 110 (6), 1328-1335

White PH (1999) Transition to adulthood. *Current Opinion in Rheumatology*, 11 (5), 408-411

White PH (1997) Success on the road to adulthood: Issues and hurdles for adolescents with disabilities. *Pediatric Rheumatology*, 23, 697-707

White PH (1997) Essential components of programs for transition to adulthood: American experience. *Review Rheum Engl Ed*, 198S-199S

White PH (1996) Resilience in children with disabilities: Transition to adulthood. *J Rheumatol*, 23, 960-962

White PH, Gussek DG & Fisher B (1990) Career maturity in adolescents with chronic illness. *J Adolesc Health Care*, 11, 372

White PH & Hackett P (2009) On the threshold to the adult medical home: Care coordination in transition. *Pediatr Annals*, 38(9), 513-20

White PH & Hackett P (in press 2009) Everyone deserves a successful future: Transition to adulthood for youth with developmental disabilities. In Voigt RG, Macias MM, Myers SM, eds. *Developmental and Behavioral Pediatrics*. Elk Grove Village, IL: American Academy of Pediatrics.

White PH & Shear ES (1992) Transition/job readiness for adolescents with Juvenile Arthritis and other chronic illness. *Journal of Rheumatology*, 19, 23

Whitehouse S & Paone M, (1998) Patients in transition: Bridging the health care gap from youth to adulthood. *Contemporary Pediatrics (Canada)*, 13-16

Wickrama KA, Conger RD, Wallace LE & Elder GH Jr (2003) Linking early social risks to impaired physical health during the transition to adulthood. *J Health Soc Behav*, 44(1), 61-74

Wiegerink DJ, Roebroek ME, Donkervoort M, Stam HJ & Cohen-Kettenis PT (2006) Social and sexual relationships of adolescents and young adults with cerebral palsy: A review. *Clin Rehabil*, 20(12), 1023-31

Wiener LS, Zobel M, Battles H & Ryder C (2007) Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: Assessing transition readiness. *Soc Work Health Care*, 46(1), 1-19

Wilber N, Mitra M, Klein Walker D, Allen D, Meyers A & Tupper P (2002) Disability as a public health issue: Findings and reflections from the Massachusetts Survey of Secondary Conditions. *The Milbank Quarterly*, 80 (2), 392+

Wiley R & Renk K (2007) Psychological correlates of quality of life in children with cerebral palsy. *Journal of Developmental and Physical Disabilities*, 19 (5), 427-44

Wilkins KL & Woodgate RL (2006) Transition: A conceptual analysis in the context of siblings of children with cancer. *Journal of Pediatric Nursing*, 21, (4), 256-65

Wilkinson J (2003) Young people with cancer-how should their care be organized? *European Journal of Cancer Care*, 12, 65-70

Williams B, Mukhopadhyay S, Dowell J & Coyle J (2007) From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis. *Social Science and Medicine*, 65(10), 2135-46

Williams RG (2009) Fumbling the handoff: Managing the transition to adult care for adolescents with chronic conditions. *J Adolesc Health*, 44(4), 307-8; comment 316-22

Williams WG & Webb GD (2000) The emerging adult population with congenital heart disease. *Pediatric Cardiac Surgery Annual of the Seminars in Thoracic and Cardiovascular Surgery*, 3, 227-233

Willoughby LM, Fukami S, Bunnapradist S, Gavard JA, Lentine KL, Hardinger KL, Burroughs TE, Takemoto SK & Schnitzler MA (2007) Health insurance considerations for adolescent transplant recipients as they transition to adulthood. *Pediatr Transplant*, 11(2), 127-31

Wills C, Scott A, Swift P, Davies M, MacKie A & Mansell P (2003) Retrospective review of care and outcomes in young adults with Type 1 Diabetes. *British Medical Journal*, 327, 260-261

Wilson KM & Klein JD (2000) Adolescents who use the emergency department as their usual source of care. *Archives of Pediatric and Adolescent Medicine*, 154, 361-365

Windle M, Grunbaum JA, Elliott M, Tortolero SR, Berry, S, Gilliland J, Kanouse DE, Parcel GS, Wallander J, Kelder S, Collins J, Kolbe L & Schuster M (2004) Healthy passages: A multilevel, multimethod longitudinal study of adolescent health. *American Journal of Preventive Medicine*, 27(2), 164-72

Wittenburg D, Fishman M & Golden T (2002) Transition Options for Youth with Disabilities: An Overview of the Programs and Policies that Affect the Transition from School. *Journal of Vocational Rehabilitation*, 17, 195-206

Wodka EL & Barakat LP (2007) An exploratory study of the relationship of family support and coping with adjustment: Implications for college students with a chronic illness. *J Adolesc*, 30(3), 365-76

Wojciechowski E, Hurtig A & Dorn L (2002) A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: A need for case management services. *Journal of Pediatric Nursing*, 17, 18-27

Woldorf JW (2007) Transitioning adolescents with special healthcare needs: Potential barriers and ethical conflicts. *J Spec Pediatr Nursing*, 12(1), 53-5

Wolf-Branigin M, Schuyler V & White P (2007) Improving quality of life and career attitudes of youth with disabilities: Experiences from the Adolescent Employment Readiness Center. *Research on Social Work Practice*, 17(3), 324

Wolff AJ, Waldman B, Milano M, et al (2004) Dental students' experiences with and attitudes toward people with mental retardation. *Journal of the American Dental Association*, 135(3), 353-357

Wolman C, Resnick MD, Harris LJ & Blum RW (1994) Emotional well-being among adolescents with and without chronic conditions. *Journal of Adolescent Health*, 15, 199-204

Wolraich ML, Wibbelsman CJ, Brown TE, Evans SW, Gotlieb EM, Knight JR, Ross EC, Shubiner HH, Wender EH & Wilens T (2005) Attention-deficit/hyperactivity disorder among adolescents: A review of the diagnosis, treatment, and clinical implications. *Pediatrics*, 115 (6), 1734-46

Woodgate R (1998) Adolescents' perspectives of chronic illness: "It's hard". *J Pediatric Nursing*, 13, 210-223

Woodgate R (1998) Health professionals caring for chronically ill adolescents: Adolescents' perspectives. *J Soc Pediatr Nursing*, 3, 57-68

Wray J & Maynard L (2008) Specialist cardiac services: What do young people want? *Cardiol Young*, 18(6), 569-74

Wynn K, Stewart D, Law M, Burke-Gaffney J & Moning T (2006) Creating connections: A community capacity-building project with parents and youth with disabilities in transition to adulthood. *Phys Occup Ther Pediatr*, 26(4), 89-103

Yelin E & Callahan LF (1995) The economic cost and social and psychological impact of musculoskeletal conditions. *Arthritis and Rheumatism*, 38, 1351-1362

Yeo M & Sawyer SM (2003) Strategies to promote better outcomes in young people with chronic illnesses. *Ann Acad Med Singapore*, 32 (1), 36-42

Yeung E, Kay J, Roosevelt GE, Brandon M & Yetman AT (2008) Lapse of care as a predictor for morbidity in adults with congenital heart disease. *Int J Cardiology*, 125(1), 62-5

Yohalem N, Wilson-Ahlistrom A, Ferber T & Gaines E (2006) Supporting older youth: What's policy got to do with it? *New Dir Youth Dev*, 111 (Fall), 117-29, 11-2

Yoos L (1987) Chronic childhood illness: Developmental issues. *Pediatric Nursing*, 13, 25-28

Young N, McCormick A, Mills W, Barden W, Boydell K, Law M, Wedge J, Fehlings D, Mukherjee S, Rumney P & Williams JI (2006) The transition study: A look at youth and adults with cerebral palsy, spina bifida and acquired brain injury. *Phys Occup Ther Pediatrics*, 26(4), 25-45

Young NL (2007) The transition to adulthood for children with cerebral palsy: What do we know about their health care needs? *J Pediatr Orthop*, 27(4), 476-9

Young NL, Gilbert TK, McCormick A, et al. (2007) Youth and young adults with cerebral palsy: Their use of physician and hospital services. *Arch Phys Med Rehabil*, 88(6), 696-702

Young NL, Steele C, Fehlings D, Jutai J, Olmsted N & Williams JI (2005) Use of health care among adults with chronic and complex physical disabilities of childhood. *Disabil Rehabil*, 27(23), 1455-60

Young R, van Beinum M, Sweeting H & West P (2007) Young people who self-harm. *Br J Psychiatry*, 191, 44-9; comment 458; author reply 458-9

Yu JW, Adams SH, Burns J, Brindis CD & Irwin CE Jr (2008) Use of mental health counseling as adolescents become young adults. *Journal of Adolescent Health*, 43(3), 268-76

Yu SM, Bellamy HA, Schwalberg RH, & Drum MA (2001) Factors associated with use of preventive dental and health services among US adolescents. *Journal of Adolescent Health*, 29, 395-405

Zacharin MR (2009) Puberty, contraception, and hormonal management for young people with disabilities. *Clinical Pediatrics*, 48 (2), 149-155

Zack J, Jacobs CP, Keenan PM, Harney K, Woods ER, Colin AA & Emans SJ (2003) Perspectives of patients with cystic fibrosis on preventive counseling and transition to adult care. *Pediatr Pulmonol*, 36(5), 376-83

Zahran HS, Zack MM, Vernon-Smile ME & Hertz MF (2007) Health-related quality of life and behaviors risky to health among adults aged 18-24 years in secondary or higher education-United States, 2003-2005. *Journal of Adolescent Health*, 41 (4), 389-397

- Zajick-Farber M** (1998) Promoting good health in adolescents with disabilities. *Health and Social Work*, 23, 203-213
- Zaslow M.J & Takanishi R** (1993) Priorities for research in adolescent development. *American Psychologist*, 38, 185-192
- Zebrack B** (2008) Information and service needs for young adult cancer survivors. *Support Care Cancer*, 2008 Jun 10. [Epub ahead of print]
- Zebrack BJ, Eshelman DA, Hudson MM, Mertens AC, Cotter KL, Foster BM, Loftis L, Sozio M & Oeffinger KC** (2004) Health care for childhood cancer survivors: Insights and perspectives from a Delphi panel of young adult survivors of childhood cancer. *Cancer*, 100, 843-50
- Zebrack BJ, Mills J & Weitzman TS** (2007) Health and supportive care needs of young adult cancer patients and survivors. *J Cancer Surviv*, 1(2), 137-45
- Zetlin AG & Turner JL** (1985) Transition from adolescence to adulthood: Perspectives of mentally retarded individuals and their families. *American Journal of Mental Deficiency*, 89(6), 570-579
- Zimmer-Gembeck MJ, Alexander T & Nystrom RJ** (1997) Adolescents report their need for and use of health care services. *Journal of Adolescent Health*, 21 (6), 388-399
- Ziring PR, Brazdziunas D & Cooley WC** (2000) The role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. *Pediatrics*, 106, 854-856
- Ziring PR, Kastner T, Driedman DL, Pond W, Barnett ML, Sonnenberg EM & Strassburger K** (1998) Provision of health care for persons with developmental disabilities living in the community: The Morristown model. *JAMA*, 260(10), 1439-1444
- Ziv A, Boulet JR & Slap GB** (1999) Utilization of physician offices by adolescents in the United States. *Pediatrics*, 104, 35-42
- Zullig KJ, Valois RF, Huebner ES & Drane JW** (2004) Evaluating the performance of the Centers for Disease Control and Prevention core health-related quality of life scale with adolescents. *Public Health Reports*, 119, 577-584