

## REFERENCES ON TRANSITION: LIST OF CATEGORIES

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With sincere thanks to NSW Transcare Project- Lynn Brodie et al

### 1. BRAIN INJURY:

Simpson, G., (2003). *You and Me. An Education Program About Sex and Sexuality After a Traumatic Brain Injury*. Brain Injury Rehabilitation Unit, South Western Sydney Area Health Service, Sydney.

Simpson G., Simons M., McFadyen M., (2002). 'The challenges of a hidden disability: Social work practice in the field of traumatic brain injury. *Australian Social Work* 55 (1), 24-36.

### 2. CARDIAC:

British Cardiac Society (2002) Grown-up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease. *Heart*; 88, 1-14

Canobbio, MM (2001) Health care issues facing adolescents with congenital heart disease. *Journal of Pediatric Nursing*, 16, 363-370

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(Feb 2), 141-6

Higgins, SS & Tong, E. (2003) Transitioning adolescents with congenital heart disease into adult health care. *Prog Cardiovasc Nurs*, 18(2), 93-8

Munro J (2005). The changing state of surgery for adult congenital heart disease. *Heart* 91;139-140

Reid,G. McCrindle, B, Ritvo,P and Webb, GD. (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* Vol 113 (3) pp e197-e205.

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. Taskforce on the management of grown up congenital heart disease (2003) *European Heart Journal* Vol 24;11, 1035-1084

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

Straatman, LP (2000) Transition to adult care in adolescents with cardiac disease. *Perspectives in Cardiology*, 16, 30-37

Webb G, D. (2003) Challenges in the care of adult patients with congenital heart disease. *Heart* 89, 465-469

Wren, C and O'Sullivan J (2001) survival with Congenital heart disease and need for follow up in adult life. *Heart*;85; 438-443

[www.childrens-heart-fed.org.uk/workshop%20transition.htm](http://www.childrens-heart-fed.org.uk/workshop%20transition.htm)

### 3. CYSTIC FIBROSIS:

Anderson, DL, Flume, PA, Hardy, KK & Gray, S (2002) Transition programs in cystic fibrosis centers: Perceptions of patients. *Pediatric Pulmonology*, 33, 327-331

Baker, K.L and Coe, L.M (1993) Growing up with a chronic condition: Transition to young adulthood for the individual with cystic fibrosis. *Holistic Nursing Practice*, 8(1) 8-15

Blum,R.W, Resnick, M.,Nelson, R and St Germaine, A (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88(2) 280-5

Borowitz, D. (1998) Cystic Fibrosis Extends CF Adult Care Program. *Commitment* – Publication of the CF Foundation

Brand, C and Sharma, N Transitional Medicine: Perspectives and Challenges form the MPPDA Committee on Transitional Care

Brumfield K, Lansbury, G.,(2004) Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a quantitative study of young Australian adults. *Disability Rehabilitation*, 18;26 (4) 223-34

Cappelli,M. MacDonald,N.E and McGrath,P.J (1989) Assessment of readiness for transfer to adult care for adolescents with cystic fibrosis. *Children's Health Care*, 18 (4) 218-24

Cowlard, J (2003) Cystic fibrosis: Transition from paediatric to adult care. *Nurs Stand*, 18(4), 39-41

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

Great Ormond Street website- information for families on Transition from paediatric to adult cystic fibrosis services

Jackson R & Pencharz PB (2003) Transition of care between paediatric and adult gastroenterology. *Cystic fibrosis. Best Pract Res Clin Gastroenterol*, 17(2), 213-35

Institute of child Health Great Ormond Street: Transition from paediatric to adult cystic fibrosis services [www.ich.ucl.ac.uk/factsheets/services/cf\\_transition](http://www.ich.ucl.ac.uk/factsheets/services/cf_transition)

Landau, L (1995) Cystic fibrosis: Transition from paediatric to adult physician's care. *Thorax*, 1995

Madge, S. Byron, M. (2002) A model for Transition from Paediatric to Adult Care in Cystic Fibrosis. *Journal of Pediatric Nursing*, Vol 17, no.4 283 - 288

Nasr, SZ, Campbell,C and Howatt, W (1992) Transition program from pediatric to adult care for cystic fibrosis patients. *Journal of Adolescent Health* 1992 Dec;13 (8): 682-5

Palys, BL (1994) Transitioning: On becoming an adult with CF International association of Cystic Fibrosis Newsletter 36,3-6

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

Stevenson, CJ, Pharoah, POD & Stevenson, R (1997) Cerebral palsy—the transition from youth to adulthood. *Developmental Medicine & Child Neurology*, 39, 226-342

#### **4. DIABETES / OTHER ENDOCRINE:**

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

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

*Diabetes Update* Autumn 2001 : Moving on up.

Eisrer C, Flynn, Green E, Havermans T, Kirby R, Sandeman D and Tooke JE (1993) coming of Age with diabetes: patients views of a clinic for under 25 year olds. *Diabetic Medicine*, 10 285-289.

Frank, M (1995) Rights to passage: Transition from paediatric to adult diabetes care. *Diabetes Care*, 16(3) 85-9

Holmes Walker, J. and Llewellyn, A. (2003) Transition Diabetes Project, Western Sydney Area Health Service. Baxter Awards . *NSW intranet site*

Hope, M. (1996) Adolescent Transition issue in Chronic Illness. Presented at annual Scientific Conference- Stomal Therapy Melbourne.

Fleming E, Carter, B and 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*, 11 560-567.

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

Kyngas H and Barlow J (1995) diabetes: an adolescent perspective. *Journal of Advanced Nursing* 22, 941-947.

National Diabetes Strategy Group. Australian Clinical Practice Guidelines: Diabetes in Children and Adolescents. (See their website)

McGill, M. (2002). How Do We Organise Smooth, Effective Transfer from Paediatric to Adult Diabetes Care? *Hormone Research* 20002;57 (suppl 1),66-68. [www.karger.com/journals/hre](http://www.karger.com/journals/hre)

Rasmussen, B, Wellard, S & Nankervis, A (2001) Consumer issues in navigating health care services for type I diabetes. *Journal of Clinical Nursing*, Vol 10, 628-34

Videntin, K. towards the development of a model of diabetes care for young adults with type 1 diabetes who are making the transition from children's to adult diabetes health services (2003). Royal District Nursing Service Research Unit, South Australia. [www.rdns.net.au](http://www.rdns.net.au)

Williams, C. (2000). Doing Health, doing gender: teenagers, diabetes and asthma. *Social Science and Medicine* 50, 387-396.

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

## **5. EPILEPSY / COMPLEX NEUROLOGY:**

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

Reeve, D.K & Lincoln, (2002) N.B coping with the challenge of transition in older adolescents with epilepsy. *Seizure* vol 11: 33-30

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

## **6. GASTROENTEROLOGY:**

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

Thomson, A. (2004). 'Position Statement: Gastroenterology Patients in Transition from Childhood to Adulthood'. [http://omge.org/guidelines/statment02/s\\_data2\\_en.htm](http://omge.org/guidelines/statment02/s_data2_en.htm)

Recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. (2002) Transition of the patient with Inflammatory Bowel disease from Pediatric to Adult Care: Medical Position Statement. *Journal of Pediatric Gastroenterology and Nutrition*

## **7. HAEMATOLOGY:**

Belling, L, Harrop, M, Kocik, S, Obstein, L, Standish, D, Vlasich, W., & Zappa, S (2003) Transition guidelines for people with bleeding disorders. *HEMAware*, 8 (4), 88-95

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

Francis, D (1995) Bridging the gaps: Adolescents with clotting disorders transition to adult care. *Nursing Network/Psychosocial News*. (Summer), 10-11

Francis, D. (1995) Bridging the Gaps: Adolescents with clotting disorders transition to adult care. *Nursing Network/Psychosocial News*, Summer 10-11

Hauser E, Dorn L. (1999). Transitioning Adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing*, 25 (5), 479-488.

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

Transition guidelines for People with Bleeding disorders. National Hemophilia foundation. [www.hemophilia.org](http://www.hemophilia.org)

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

### **8. HIV / AIDS:**

Lyall, H. (2004) Growing up, Gaining Independence. Principles for Transition of HIV Care. [www.bhiva.org/chiva/protocols/adolescent.html](http://www.bhiva.org/chiva/protocols/adolescent.html)

Miles, K, Edwards, S & Clapson, M (2004) Transition from paediatric to adult services: Experiences of HIV-positive adolescents. *AIDS Care*, 16(3), 305-14

### **9. INBORN ERRORS OF METABOLISM:**

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

Website: University of Washington PKU Clinic, Seattle  
[http://depts.washington.edu/pku/pro\\_info/protocols/transition.htm](http://depts.washington.edu/pku/pro_info/protocols/transition.htm)

### **10. INTELLECTUAL DISABILITY:**

Kastner, T. (1991) Who cares for the young adult with mental retardation? *Developmental and Behavioural Pediatrics*. 12 (3) 196-98

### **11. RENAL:**

Cameron, JS (1985) The continued care of pediatric patients with renal disease into adult life. *American Journal of Kidney Disease*., 6(2): 91-95

Myers, PS (2002) Transitioning an adolescent dialysis patient to adult health care. *Nephrol Nurs J*, 29, 375-6

### **12. RHEUMATOLOGY:**

Chamberlain, MA, Rooney, CM (1996) Young adults with arthritis: Meeting their transitional needs. *British Journal of Rheumatology*, 35, 84-90

Chira, P. and Sandborg C.(2003)Adolescent Rheumatology transitional care:steps to bringing health policy into practice *Rheumatology Vol 43, 6;*

Leak, A.M. (2000) Improving adolescent rheumatology services in the UK. *Rheumatology* 39; 575-579

McDonagh J, Southwood T, Ryderz C. (2000). Bridging the gap in rheumatology. *Annals of Rheumatological Disease*, 59, 86-93.  
About arthritis: [www.arc.org.uk](http://www.arc.org.uk)

Rettig, P. Atheya, BH. (1991) Adolescents with chronic disease: Transition to adult health care. *Arthritis Care Res* 72:174-9

Shaw, KL Southwood, TR and McDonagh, JE (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: results of a Delphi study. *Rheumatology* (in press)

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

### **13. SPINA BIFIDA:**

A constant fight – the need for accessible and coordinated services for children and adults with hydrocephalus and /or spina bifida. [www.asbah.org/report.html](http://www.asbah.org/report.html)

Blum,R.W, Resnick, M.,Nelson, R and St Germaine, A (1991) Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88(2) 280-5

Johnson,C., Dorval,J. Transitions into Adolescence. *Spina Bifida Association of America Fact Sheet*. <http://www.sbaa.org>

Moving On – Transition from the Children’s Hospital to the Adult world – Spina Bifida Unit  
Children’s Hospital at Westmead

Peterson, P.M Rauen, K.K, Brown, J and cole, C. (1994) spina bifida: The transition into adulthood begins in infancy. *Rehabilitation Nursing* 19(4) 229-37

Sawyer,S.Collins, N.Bryan,D.Brown,D.Hope,M. Bowes, G. (1998) Young People with Spina Bifida; Transfer from Paediatric to Adult Health Care. *Journal of Paediatrics and Child Health*, 34 (5) 414-417

Transition to independence: <http://enabledonline.com>

Tuffrey, C and Pearce A. (2003) Transition from paediatric to adult medical services for young people with chronic neurological problems. *Journal of Neurology Neurosurgery and Psychiatry* &4: 1011-1013

### **14. SPINAL:**

Anderson, CJ, Johnson, KA, Klaas, SJ, & Vogel, LC (1998) Pediatric spinal cord injury: Transition to adulthood. *Journal of Vocational Rehabilitation*, 10, 103-113

Thetford, A.(1999) Transition of Spinal Dysfunction Patients from Princess Margaret Hospital for Children to Adult Services (unpublished)

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