



Education and Culture DG

Lifelong Learning Programme

Leonardo da Vinci

# TRANSITION

[www.leonardo.org.pl](http://www.leonardo.org.pl)

[www.leonardo.org.uk](http://www.leonardo.org.uk)

[www.leonardodavinci.nl](http://www.leonardodavinci.nl)

Jillian Archer

Senior Physiotherapist

Regional Disability Team

Walkergate Park

International Centre for Neuro-rehabilitation and Neuro-psychiatry

Newcastle-upon-Tyne

**Community Rehabilitation in Neurology Training Programme**



Education and Culture DG

Lifelong Learning Programme

**Leonardo da Vinci**

Presented educational materials were developed in 2008-2010 with support from European Union funds as a part of the Leonardo da Vinci project titled: Community Rehabilitation in Neurology Training Programme



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

---

“We cannot always build the future for our youth but  
we can build our youth for the future”

*Franklin D Roosevelt 1882-1945*



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## In the United Kingdom Transition is currently being recognised as an important issue

This is for several reasons:

- Children are now surviving into adulthood with conditions that previously would have been lethal and also would have not been known to, or would be rare in, adult services. While *et al 1996* and now need lifelong management *eg Gardner et al 1997*
- Often these young people would need the expertise of multiple specialists and the paediatrician takes an holistic overview and co-ordinating role in their care and also in the needs of the family. Is this role available within adult services?
- Lack of appropriate services - An article by *Ko and McEnery in 2004 states that after assessment of 14 young people in London out of the need of 49 referrals to adult services needing to be made they were unable to make 17 because the service did not exist. They found that particularly adult physiotherapy and occupational services were particularly under-provided for people with physical difficulties*



DG Edukacja i Kultura  
Program „Uczenie się przez całe życie”  
Leonardo da Vinci

## In the United Kingdom Transition is currently being recognised as an important issue; cont

This is for several reasons:

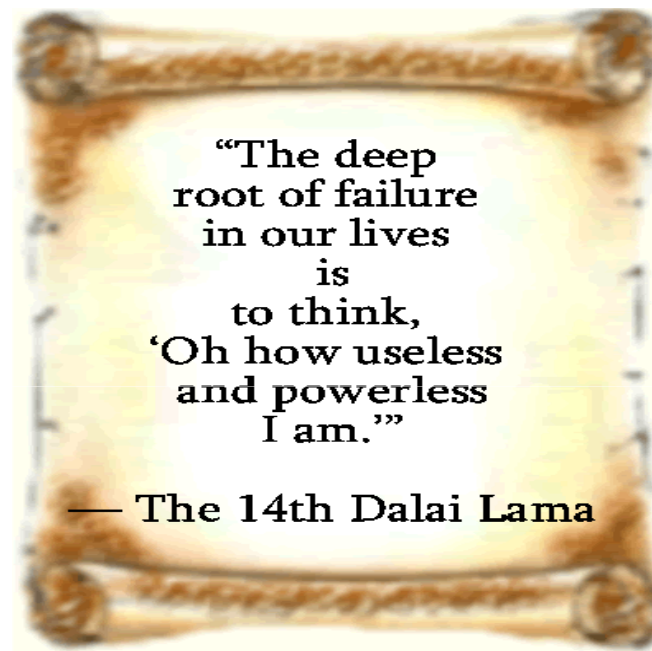
- All young people with health needs are at risk during transition and those with Neurological disorders and disabilities are those least well served.
- Poorly planned transition can be associated with non-adherence to treatment and loss to follow-up in adult services with obvious possible serious consequences *Bax et al 1988, Cathels & Reddihough 1993, Tomlinson & Sugarman 1995, Watson 2000*
- *Adults with complex physically disabling conditions from childhood have ongoing health needs that require frequent input. A 2005 study in Canada by Young et al found that their admission rate is 9 times that of the general population*



DG Edukacja i Kultura  
Program „Uczenie się przez całe życie”  
Leonardo da Vinci

## How do the Young People feel?

- Dumped
- Abandoned
- Thrown out
- Hurtling into a void
- Cut off
- Sudden
- Lost in a shuffle
- Tossed out



*Morris 1999; Shaw 2004; Scott 2005*





DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# Vision

- Young people supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and well-being.
- Young people taking responsibility for their own health and making informed choices and decisions regarding their emotional and social development, and health and well-being both now and in the future
- Services and staff who are able to respond in a sensitive way which encourages engagement and provides high quality support for young people



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

“When I was a boy of fourteen, my father was so ignorant I could hardly stand to have the old man around. But when I got to be twenty-one, I was astonished at how much he had learned in seven years”. Mark Twain, "Old Times on the Mississippi" Atlantic Monthly, 1874

“I have found the best way to give advice to your children is to find out what they want and then advise them to do it”. Harry S. Truman, 1884-1972





DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

The joys and perils of adolescence have been the subject of innumerable witty observations as well as a fair amount of mythology but

- In all societies the passage from childhood to adulthood is marked in various ways but all recognise that the Young Person has to take on new duties and responsibilities.
- In the Western world this process is protracted and complicated because of the wide range of opportunities and choices that are available –
- *Education*
- *Careers*
- *Employment*
- *Mobility*
- *Relationships*
- *Independence*
- But for the increasing numbers of Young people with long-term health problems this is a bigger challenge and this is made more difficult than it needs to be because of the health professionals lack of adequate planning of the handover of health care to the adult-orientated care system



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

The journey into adult life is a time of profound psychological and social change for all young people and their families *Eiser 1993,*

but for young people with long-term care needs, the transition is often made more difficult by both changes in their care needs and access to services  
*While et al 2004*



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

---

- Transition for young people with medical needs is often made more difficult than it needs to be because health professionals do not adequately plan the one aspect of care which is in their control – the process of handover to adult services. Often this is not a process of handover but an abrupt transfer. At the worst end of the spectrum there are no arrangements made at all!
- 40% of Young people had minimal or no involvement in the transition planning process *Heslop 2002*



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## But What is Transition?

- **Transition** can be defined as a “purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems”.



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## And What is Transfer?

**Transfer** is an event, not a process. This term is often used to describe handover.



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# Government

There are several Government papers and guidelines which aim to give guidelines to Health services in the UK about how to improve services to Young People in what is an important stage of their lives, not only medically but also educationally and socially.

- National Service Framework for Children, Young People and Maternity services
- Transition: Getting it Right for Young People (2006)
- White Paper, Choosing Health: Making Health Choices Easier
- White paper – Our health, Our Care, Our say (2004)
- Department of Education and Skills Green Paper, Youth Matters
- Transition Guide for All services (2007)
- Moving on Well (2008)





DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# Other Policy and Consensus Statements

## **Government other papers**

- You're welcome
- Youth Matters
- Every Child Matters
- Transitions: Young adults with Complex needs

## **Professional Bodies**

Royal Colleges

- - Getting it Right for teenagers in your practice (RCN & RCGP)
- - Adolescent Transition: Guidance for nursing staff (RCN)
- - Bridging the Gap: Health Care for Adolescents (RCPCH)

British Medical Association

- - Adolescent health

## **International**

- American Academy of Paediatrics
- Canadian Paediatric Society



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## National Services Framework for Children, Young people and Maternity services

- NSF emphasises the importance of better care for adolescents.
- Emphasises the responsibility of the Health service to improve training and expertise in what it terms a neglected area
- To ensure that young people experience a smoother, less stressful transition between clinical services
- Also stresses a wider perspective, taking into account the other aspects of transition planning eg. Education and person-centred planning

[www.leonardo.org.pl](http://www.leonardo.org.pl) [www.leonardo.org.uk](http://www.leonardo.org.uk) [www.leonardodavinci.nl](http://www.leonardodavinci.nl)



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# Communication

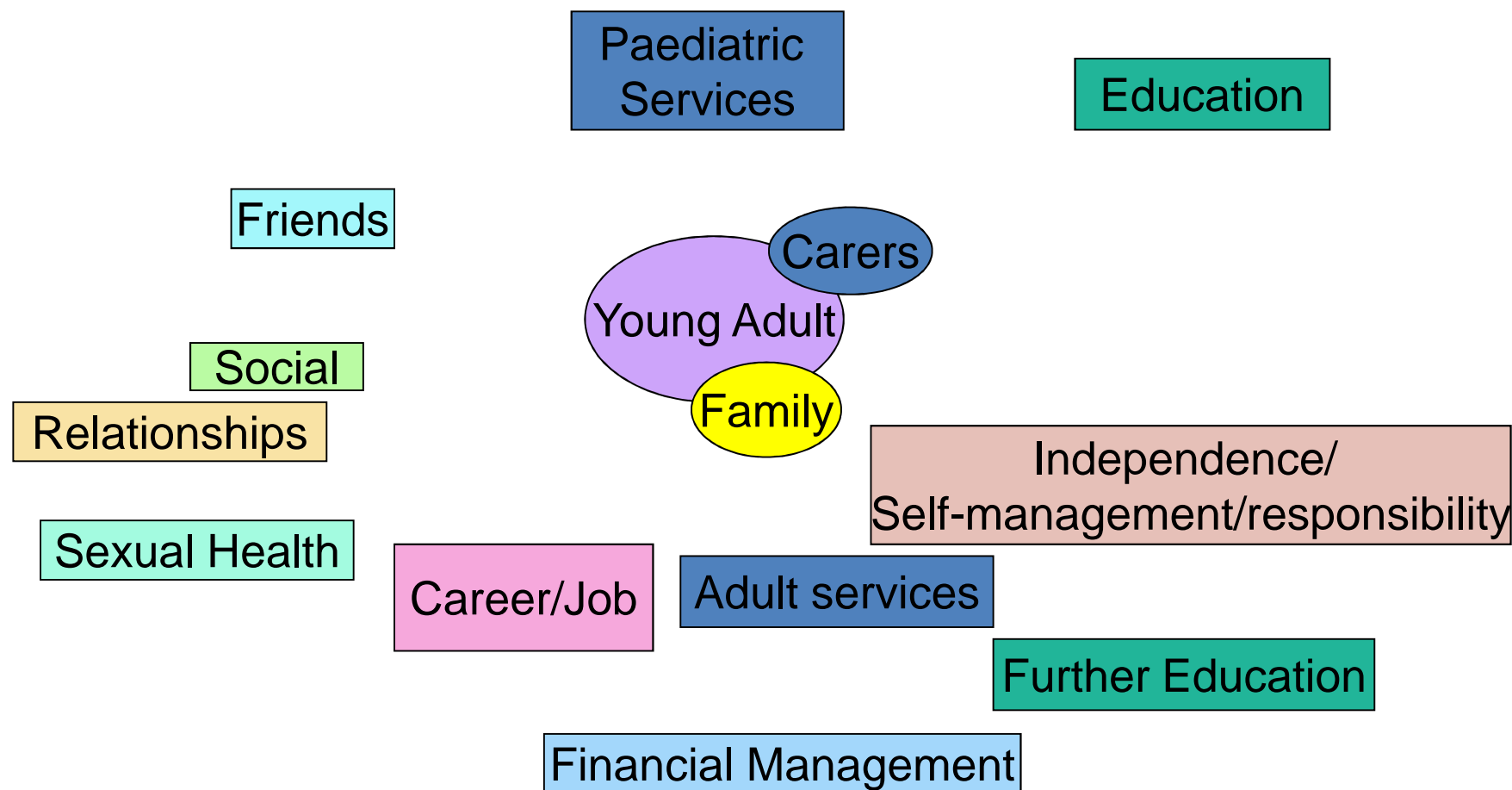
- We all know from a personal perspective that it takes time to build up confidence in a new doctor
- The approach of an adult services practitioner is direct to the young person whereas the approach of the paediatrician is primarily via the family.
- It is not surprising that this move, to a perceived as unfriendly environment, can cause great anxiety, not only for the young person but also for the family.
- “If you have been with them a long time, the same person, you get a little bit of attention, and you do ask more questions, but... When you’re jumping from pillar to post, like I was seen by six doctors in one year, then I just didn’t want to talk to them, but if you stay at the same doctor you tend to get a bit closer, to open out.”



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci



Community Rehabilitation in Neurology – Training Programme

[www.leonardo.org.pl](http://www.leonardo.org.pl) [www.leonardo.org.uk](http://www.leonardo.org.uk) [www.leonardodavinci.nl](http://www.leonardodavinci.nl)



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# What do Young People need to improve Transition

- Help in developing skills in communication
- Decision making
- Assertiveness
- Self-care, including sexual health
- Help in managing social, educational, and employment opportunities and challenges
- Help to develop independent living skills, including money management.
- Parents also value support, information and guidance in advocacy



[www.leonardo.org.pl](http://www.leonardo.org.pl) [www.leonardo.org.uk](http://www.leonardo.org.uk) [www.leonardodavinci.nl](http://www.leonardodavinci.nl)



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# Successful Transition

- Well planned transition improves clinical, educational and social outcomes
- And is dependent on collaboration between paediatric and adult services.

[www.leonardo.org.pl](http://www.leonardo.org.pl) [www.leonardo.org.uk](http://www.leonardo.org.uk) [www.leonardodavinci.nl](http://www.leonardodavinci.nl)





DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# Models of Transition

- Several models but no clear evidence of which is best
- Different approaches for different conditions



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## These Models Include

- The Simplest Model - A dedicated follow-up service provided within the adult setting without a combined paediatric-adult clinic with no direct input or continuity from paediatric services
- A “seamless” clinic which begins in childhood or adolescence and continues into adulthood, with both child and adult professionals providing ongoing care as appropriate.
- Life-long follow-up in the paediatric setting – this sometimes happens by default in disability services eg Cerebral palsy (Learning disability), Duchenne Dystrophy or Down’s Syndrome
- A generic transition team within a children’s hospital. 1 or 2 dedicated health professionals ensuring that all young people in the different specialities go through appropriate transitions.
- Generic transition co-ordinators for larger geographical regions. May be appropriate for conditions which are relatively rare or for co-ordinating links between Children’s Hospitals and local general Hospitals



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## What is Involved in a Good Model?

- Recognition of the importance of the process
- Adequate consultation with professionals and service users
- Flexibility of Timing — *dependent on developmental readiness, health status, capability of adult service providers, not when the disease process is active eg Cancer*
- A period of preparation for the young person and their family
- Information on the transfer - details of adult services in adolescent clinics, information on their rights eg consent and confidentiality, information about effective ways of dealing with medical situations
- Monitoring of attendance until the Young Person is established in adult services



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# What is Involved in a Good Model? Continued

- Professionals may need to further develop their knowledge and skills in working with young people
  - biology and psychology of adolescents
  - communication
  - consultation strategies
  - multi-disciplinary working and multi-agency working

These are by no means the whole of what is needed but indicate the amount and the breadth of what is required



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# Transition Plans

Successful transition planning is person-centred and recognizes that the person's needs will change over time. It may be a simple or complex process depending on the young person's condition and the range of services required.

[www.leonardo.org.pl](http://www.leonardo.org.pl) [www.leonardo.org.uk](http://www.leonardo.org.uk) [www.leonardodavinci.nl](http://www.leonardodavinci.nl)



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

---

- The development of a Transition plan has a role in helping the young person navigate their way around the health and social care system
- The plan should be developed by the young person themselves, supported by the most relevant health professional/key worker who can help them review it regularly.

[www.leonardo.org.pl](http://www.leonardo.org.pl) [www.leonardo.org.uk](http://www.leonardo.org.uk) [www.leonardodavinci.nl](http://www.leonardodavinci.nl)





DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# What Should be in a Transition Plan?

- A List of the Team plus Review dates
- A Self-Assessment identifying whether they understand or need help with various areas or indeed if there is an action plan. Examples of these areas could include confidentiality, whether they need help to explain their needs, do they want to be seen alone and do they know the names of their Health care professionals



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

- **Health** What is the understanding of their own health /condition?
- Do they know with whom and when they have appointments
- Do they understand their medication
- Do they know how to contact their family Doctor
- Do they understand the signs and symptoms of their condition and their effects
- Do they know how to contact their dentist and the importance of dental care, the importance of diet, skin care and exercise
- The effects of smoking and drinking and misuse of drugs
- Do they know what to do if someone harms, threatens or behaves inappropriately
- **Sexual Health** Do they understand about the changes in their body, sex and relationships, prevention of pregnancy (how and where to get it), and sexually transmitted diseases



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

- **Self-Care Skills** Can they carry out various self-care skills or do they need help? Do they use equipment?
- **Mobility** Can they get around indoors and outdoors? Do they walk, do they use a wheelchair. Are they independent or do they need help? Can they drive?
- **Home Management** Do they know how to buy food and clothes, manage a budget, look after their clothes (washing), prepare a meal, do housework?
- **Housing, Work, Leisure and Education** Do they know what their housing options are and where to go, do they have a career plan, do they have friends of their own age, can they meet with them, do they have leisure activities they enjoy, are they able to try new activities, do they know where to go for support?



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## What is the Next Step for RDT\*?

- Combined clinics with paediatrics?
- Representation in Paediatric Clinics?
- Special Clinics within the RDT\*?
- Information about RDT\* in Paediatric Clinics?
- Open days?
- Partnership working with other agencies?
- Education days?

*\*RDT - Regional Disability Team*



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## Next Step?

- Independence
- Vocation/Employment
- Self –direction/responsibility
- Comprehensive transfer of medical records (make sure Doctor has read them before seeing young person)
- What else/Other ideas?



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## What about Transition at the other end of the Age Scale????

- Again due to advances in medicine and in general care people are surviving into old age with problems that this group of specialists will not have seen before.
- Also problems increasingly complex with aging process overlay

[www.leonardo.org.pl](http://www.leonardo.org.pl) [www.leonardo.org.uk](http://www.leonardo.org.uk) [www.leonardodavinci.nl](http://www.leonardodavinci.nl)





DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

## How do we plan for this?

- ? Joint working before age 65? At age 65?
- Elderly care specialists may need education in the person's neurological condition and how to manage it eg Spina Bifida, Cerebral palsy, Hereditary Spastic Paraplegia, Multiple Sclerosis.
- We need support in how to recognise which of their symptoms are due to the aging process.
- The person requires support through a time of change physically and also psychologically as their support network changes from the familiar to the unfamiliar.



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

---

- Should Services become Diagnosis specific?
- But we then we need to brush up on the aging process.
- A few thoughts!



DG Edukacja i Kultura

Program „Uczenie się przez całe życie”

Leonardo da Vinci

# References

- Most references are to be found in UK Government papers, in particular
- National Service Framework for Children, Young People and Maternity services
- Transition: Getting it Right for Young People (2006)
- Moving on Well (2008)
- They can be found on [www.dh.gov.uk](http://www.dh.gov.uk)
- For such an important issue there is little research!