

PEATC
Parent Educational Advocacy
Training Center



Virginia's NEXT STEPS Transition Program for
Families, Youths, and Professionals:
Building Effective Partnerships and Accessing
Resources

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Rights, Risks and Responsibilities

Thinking About Guardianship and
Decision Support
Sue Swenson

Full disclosure: I am a mother

- I am not a lawyer
- There are many informational resources on the web
- Other parents are a source of wisdom
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The Struggle for Rights of
People with Disabilities

- Deficit, difference and deviance
- Eugenics
- Institutionalization, segregation
- Normalization
- Program, plan, readiness
- Equality and inclusion

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Emerging Rights of People
with Disabilities

- Human rights movement
- Parent movement
- Civil rights movement
- Disability movement
- Self-advocacy

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Some Statements of Rights

- Developmental Disabilities Services & Bill of Rights Act
- Americans with Disabilities Act
- Olmstead S.C. Decision
- IDEA
- Montreal Declaration on the Rights of People with Intellectual Disabilities in Health Care
- UN Convention on the Rights of People with Disabilities



Whose life is it, anyway?

- The right to diagnosis & treatment
- The right to safety and security
- The right to live in the world



Kinds of Decisions

- Personal taste
 - Color of my room or clothing
 - What to do for fun
 - Whom to love
- Expert input
 - Whether to have surgery
 - How to manage money
 - Whether to marry



What are the risks?

- As parents, we worry about . . .
 - Health status
 - Accidents and injuries
 - Abuse and neglect
 - Loneliness and isolation
 - Violence and crime



The Dignity of Risk

“Overprotection may appear on the surface to be kind, but it can be really evil.”

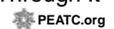
Robert Perske



The Duty of Love

- “It is true we can seldom help those closest to us. Either we don't know what part of ourselves to give or more often than not, the part we have to give is not wanted. . . We can love completely, without complete understanding.”

--Norman Maclean, A River Runs Through It



Models of Decision Support

- From least to most restrictive
- From temporary to permanent
- From specific to plenary
- With a goal of preserving rights



Supported Decision-Making

- Use accommodations to support someone to decide & communicate
- Use more accommodation for more important or difficult decisions
- Allow for choice
- Allow for trust
- Allow for relationships



We All Use Decision Support

- When we use experts like lawyers, doctors or accountants.
- When we seek advice from friends and family.
- When we seek counsel from wise people such as clergy members.



So

- Why should people with disabilities need a guardian just because they can't manage alone?



Person-Centered Thinking

- Circles of support
- Shared decision-making
- The right support for the right task
- Try to understand
- Be open to questions
- Strengths and support needs
- Dreams and nightmares



Support Choices

- Early in life: Ask, "So what?"
- It's never too late
- Learn to listen
- Develop your confidence
- Encourage others to participate



Other strategies

- Power of attorney
- For specific purposes such as health care
- Given by the person; may be taken back
- Special needs trust
- Fund what is important to you
- Fund what is important to the person
- May be pooled (WA is state-sponsored)



Other strategies

- Representative payee for financial management
- Use technology
- To connect and communicate
- To supplement information



A new way of thinking

Guardianship, at one time seen as a benign way to "protect" people with disabilities, is now seen as an intrusion into a person's basic civil and human rights and a legal process to be avoided.

-- Hoyle and Harris, Alternatives to Guardianship



Why Guardianship?

- Questions of custody or legal status
- History of guardianship
- Breakdown of supports
- No exposure to alternatives
- Legal or financial advice



Duties of the Guardian

- Work within state law & scope of guardianship order
- Consider the values and preferences of the individual
- Encourage participation of individual and help him or her regain capacity
- Minimize restrictions



Recommended Reading

- National Guardianship Association Standards of Practice www.guardianship.org
- Person-centered planning, The Quality Mall www.qualitymall.org
- "Re-thinking Guardianship" Dohn Hoyle and Kathleen Harris
- "The Dignity of Risk," Robert Perske



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