



Family Quality of Life throughout the Life Span: Eight Lessons Learned in 158 Years

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Definition of Family Quality of Life

- Family members' needs are met.
- They enjoy their life together.
- They have a chance to do the things that are important to them.



Family Quality of Life Domains

Domains
Physical/Material Well-Being
Parenting
Family Interaction
Emotional Well-Being
Disability-Related Support



Extent of Satisfaction

- Domains of greatest satisfaction
 - Parenting
 - Family interaction
- Domains of least satisfaction
 - Emotional well-being
 - Disability-related support



Summary of Global Family Quality of Life Research

- Four characteristics associated with higher family quality of life:
 - Higher family income/income supplements
 - More support from family, friends, and community
 - More effective disability-related services
 - Stronger trusting partnerships with professionals





Lesson 1: Welcome & dignify



Dignity

- Being treated with respect
- “Less able is not less worthy.”



<https://youtu.be/H8N7uVOQTDU>



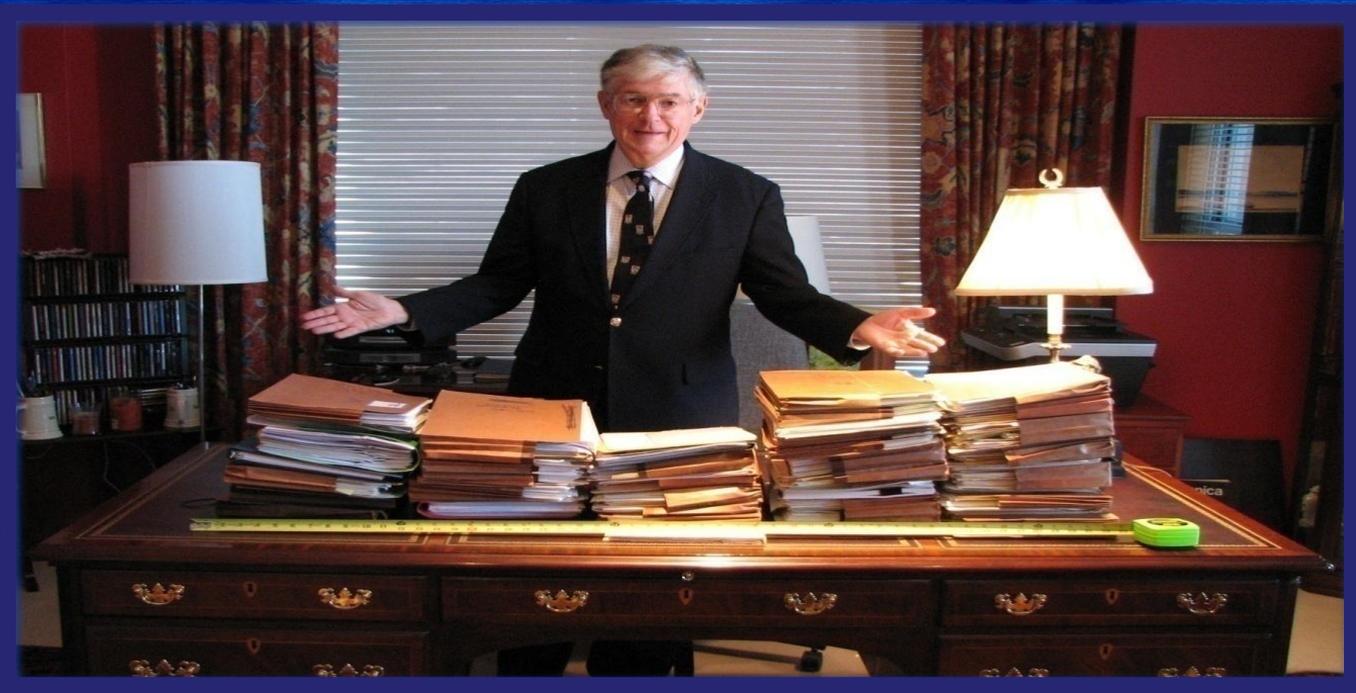
Lesson 2: Embrace complexity of rights and advocacy



Parents Knowing Their Rights

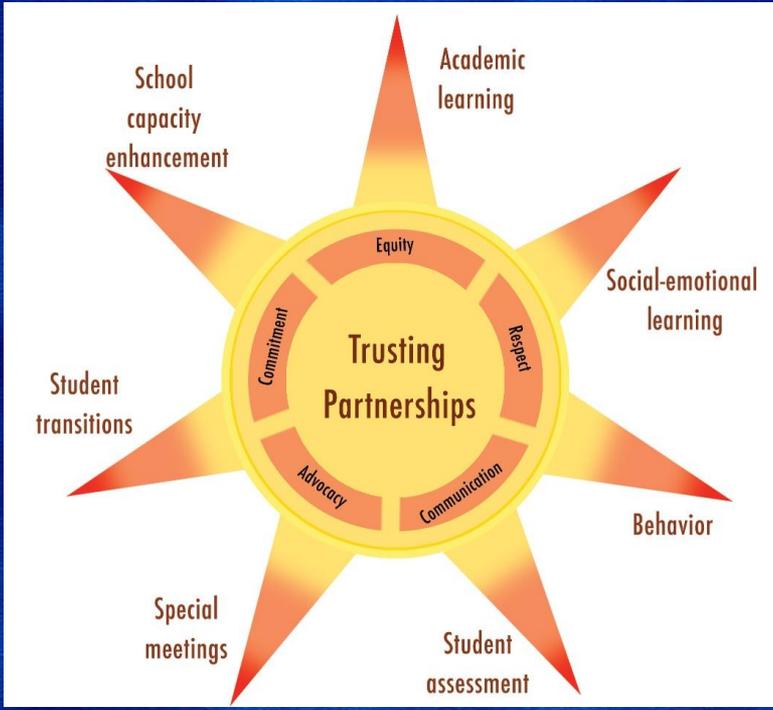
- Over last 8 years, averaging 90%
 - Completely
 - Almost
 - Somewhat
 - A little
 - Not at all
- Lori's story

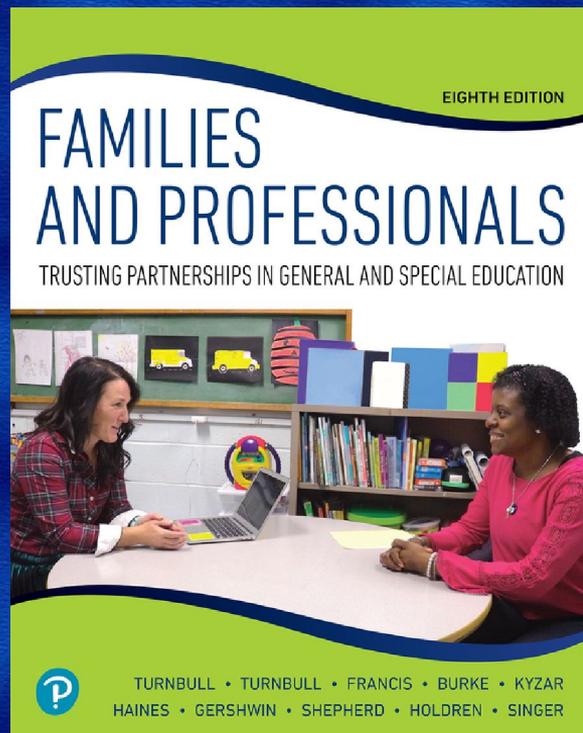






Lesson 3: Build trusting partnerships





<https://www.pearson.com/store/en-us/pearsonplus/p/9780136768715.html>



Lesson 4: Enhance belonging





<https://www.youtube.com/watch?v=q6DHSqhJcCA>

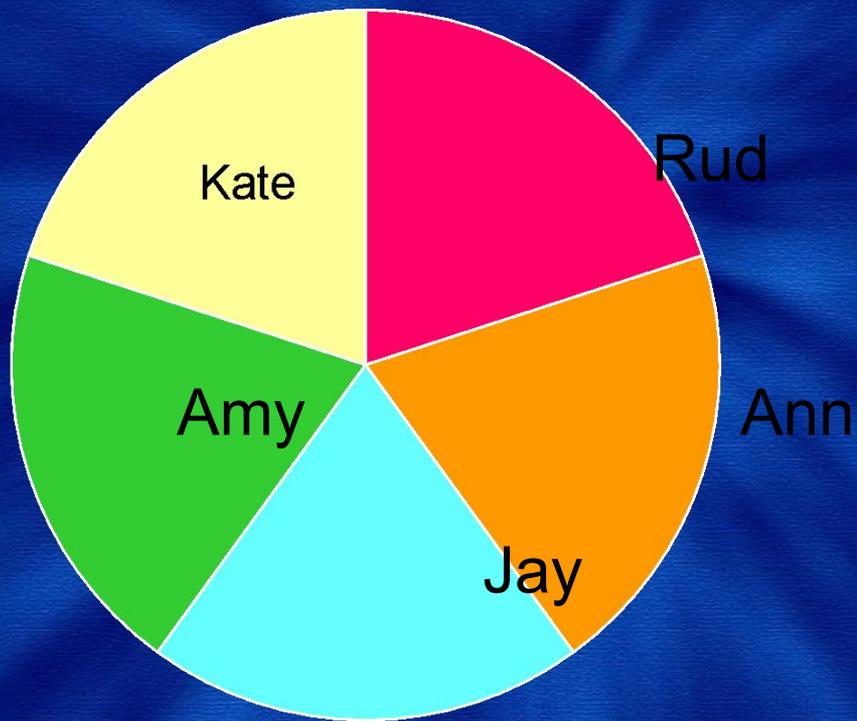


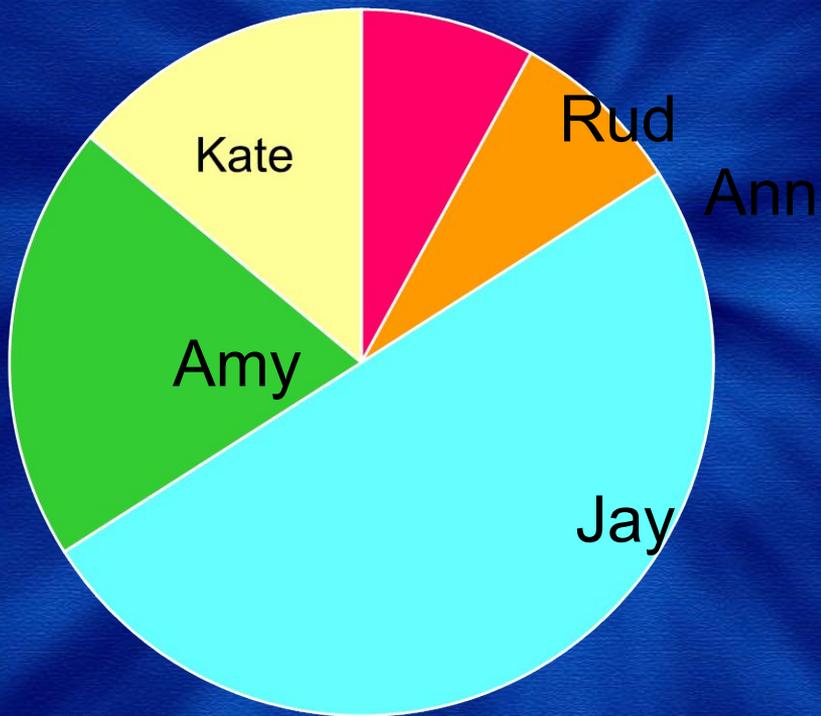
IDEA's Preamble

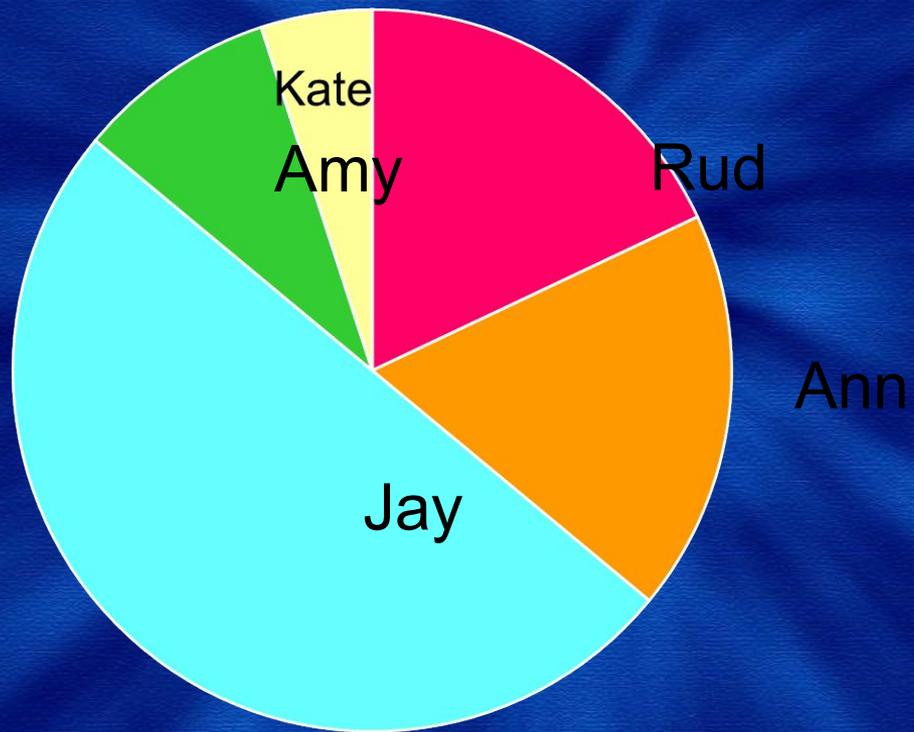
“Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in and contribute to society.”



Lesson 5: Balance interests of every family member









Lesson 6: Presume competence & envision great expectations







Lesson 7: Build a village

Week at a Glance

Time	Mon	Tues	Wed	Thur	Fri	Sat	Sun
12-8:30 AM	F	H	H	H	H	H	H
8-8:30	F	H	C1	C4	C1	C1	H
8:30-9 AM	C1	H	C1	C4	C1	C1	F
9-9:30 AM	ST	H	C1	C4	C1	C1	F
9:30-10 AM	ST	H	C1	C4	C1	C1	F
10-10:30 AM	MS	H	C1	C4	C1	C1	F
10:30-11 AM	MS	YT	C1	C5	C1	C6	F
11-11:30 AM	H	H	C1	C5	C1	C6	F
11:30-12 PM	JC	JC	JC	JC	JC	C6	F
12-12:30 PM	JC	JC	JC	JC	JC	C6	F
12:30-1 PM	JC	CW	JC	JC	CW	C6	F
1:30-2 PM	JC	JC	JC	JC	JC	C6	F
2-2:30 PM	JC	JC	JC	JC	JC	C4	F
2:30-3 PM	JC	JC	JC	JC	JC	C4	F
3-3:30 PM	JC	JC	JC	JC	JC	C4	F
3:30-4 PM	H	C2	H	C5	H	C2	F
4-4:30 PM	H	C2	H	C5	H	C2	F
4:30-5 PM	H	C2	H	C5	H	C2	F
5-5:30 PM	H	C2	ER	C5	H	C2	F
5:30-6 PM	H	C2	ER	C3	C5	C2	F
6-6:30 PM	H/MT/GF	C2	ER	C3	C5	C2	F
6:30-7 PM	H/MT/GF	C2	ER	C3	C5	C2	F
7-7:30 PM	MT/GF	MT	C3	C3	H	C2	F
7:30-8 PM	MT/GF	MT	C3	C3	H	C2	F
8-8:30 PM	H	H	H	C3	H	C2	F
8:30-9 PM	H	H	H	H	H	C2	F
9-11 PM	H	H	H	H	H	H/C?	F

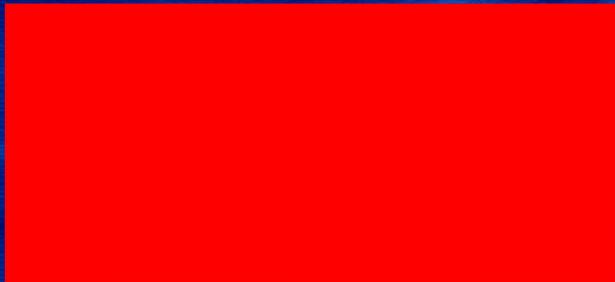
Sleep
Personal Care
Work
Leisure/Comm. Part.
Bkt/Lunch/Dinner
Speech Therapy
Music Therapy
Massage
Yoga
Church

H – Housemates	JC – Job Coach
F – Family	C1-C6 – Companions
ST – Speech Therapist	FR – Fraternity
MT – Music Therapist	GF – Girlfriend
M – Masseuse	CW – Co-Workers
Y – Yoga Teacher	



TAXI







Lesson 8: Pursue joy



https://www.youtube.com/watch?v=fxy8C6AaW_w



“If youth knew; if age could.”



If from early childhood years, professionals teach and families adopt these lessons, we celebrate what families' quality of life will be across the full lifespan.

