# Us and Them: Understanding the Family Experience and Making them Your Most Valuable Partner

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#### Having a Child with a Significant Disability

**Initial Emotions** 

- Denial
- Anger
- Guilt
- Fear/Uncertainty
- Strength



#### Having a Child with a Significant Disability

Real World Impacts

- Marriage
- Employment
- Finding healthcare
- Finding Supports
- Social Relationships



#### **Large Group Question**

## What do you currently do that helps families be a partner in the employment process?

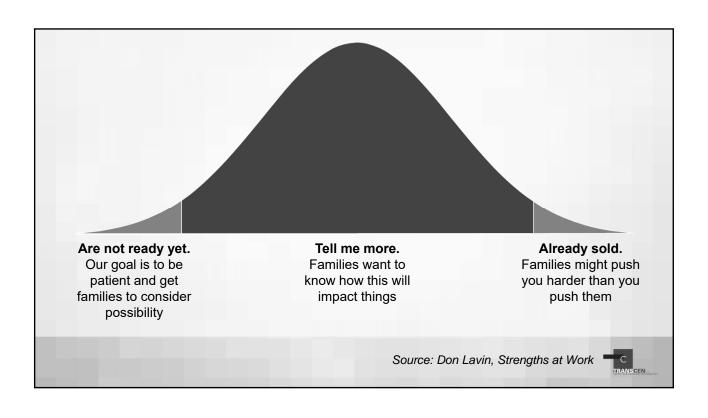


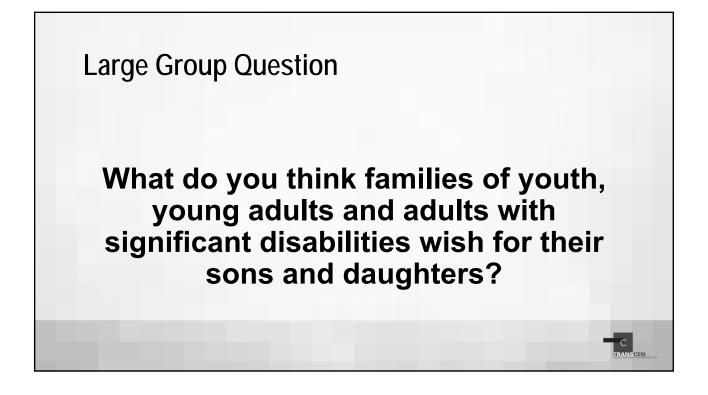
#### **Reasons for Resistance to Employment**

- Fear of disruption
- · Mistrust of system
- Wariness of professionals
- Concerns over vulnerability and safety
- Lack of belief in ability to work
- Myths about benefits
- What others have you heard?











#### **Common Pitfalls**

- The myth of "letting go"
- Lack of communication
- Cross purposes
- Now Now Now!!
- Not caring or being invested
- Not understanding the impact of disruption



#### Strategy 1: Root Yourself in High Expectations

#### A two-way street

- Helping families see that employment is possible for people with all types of disabilities
- 2. Helping professionals believe the same thing and convey positive messages

#### It's not always easy.





#### Strategy 2: Relationships

#### Building honest, two-way relationships is the most crucial element of effective family engagement

- Parents want to know that you know their son/daughter
- No relationship = Defaulting to "I have to do this myself"
- · Takes time and effort



#### **Strategy 3: Seeing Youth in a Different Way**

Can you help move parents from low expectations to seeing possibilities?

- Positive Personal Profile
- Positive Picture (WI)
- Be patient it's a big leap for some
- Generational or cultural considerations



#### **Strategy 4: Create a Family Support Plan**

What needs to happen to make CIE work for families?

- Acknowledge fears of potential impact
- Negotiate risk taking
- Explore braiding of services to fill holes in the day
- Have solid plan: "What will happen if something goes wrong?"



#### **Strategy 5: Benefits Counseling**

Fear of losing benefits, or a family reliance on the benefit check continues to be a big barrier.

- Working improves quality of life
- Working tends to lead to more \$\$\$
- Acknowledge that SSI is hard to navigate
- Partner with or become a CWIC



#### **Strategy 6: Staff Training**

Your staff needs training on how to effectively engage families.

- Does not always come naturally
- Build into staff performance expectations
- Engage partners to help



#### **Lessons For the Future**

(Butterworth et al - T-TAP Mentor Guide)

Consider these strategies that employment providers and agencies can implement.

### Lesson 1 Establish *clear and uncompromising* goals

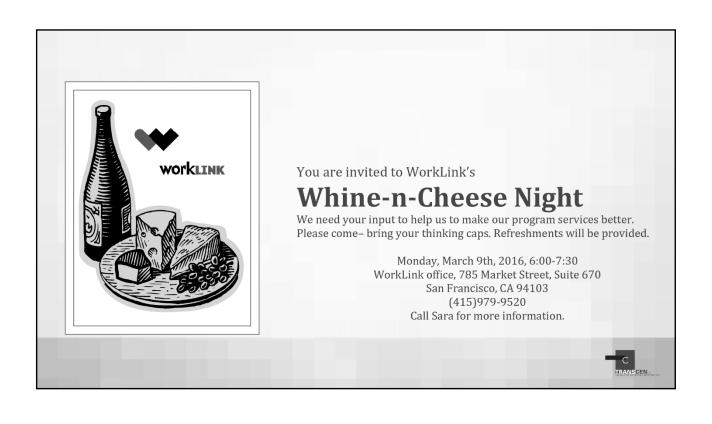


#### Lesson 2

Communicate expectations to everyone, and communicate often.

- Staff
- Board
- Administration
- Partners
- Community





#### Lesson 3

Reallocate and restructure resources

"You can look at an agency's budget and know what they really prioritize."



#### Lesson 4

Just do it! Find jobs one person at time, one business at a time.

- One of the best ways to build better partnerships with families is to be good at what you do.



#### Lesson 5

Develop partnerships – internal and external.

- Assign parent lead
- Partner with advocacy orgs for training
- National technical assistance



#### **Final Large Group Question**

Now that you have heard the information, what is one or two action steps you or your organization can take immediately to help improve partnerships with families?



#### Thank you!!!

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