• Mom of 3 sons, “Ben’s mom”
• MO Partners 1999
• CtLC Nexus at UMKC-Institute for Human Development, UCEDD
  • Product Development and Training
  • Trainer/Coordinator of activities focusing on supported decision making
Outcomes for Today

• Briefly explain the Charting the LifeCourse Framework
• Explore the CtLC Principle of Trajectory
• Share examples of how other families in MN are using the Trajectory
What is Charting the LifeCourse?

Created for people and families of all abilities and all ages to:

• Explore life possibilities
• Share ideas, hopes, and fears
• Set higher expectations
• Navigate Future
• Advocate for Vision
• Problem-Solve and Plan
Charting the LifeCourse Framework and Principles

www.lifecoursetools.com
CORE BELIEF
All people and their families have the right to live, love, work, play, learn, and pursue their life aspirations in their community.
Life Trajectory, Vision and Experiences

www.lifecoursetools.com
What is YOUR Vision for a Good LIFE?

Vision of What I Want
What DON’T You Want??

Vision of What I Don’t Want
Vision & Trajectory for a Good Life

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Vision of What I Don’t Want
Ben’s Good Life Vision

- Family
- Friends
- TATTOOS
- Vacations
- Girlfriend
- Concerts
- WWE
- NASCAR
- Money
- Job/own business
- Fire Station
- Church
- Tiger Football
- Royals
- Good Food
- Pepsi
- Beer
- Active
- Healthy & Fit

Poverty/No Money
Poor Health
Diabetes
Heart Disease
Guardian
Isolated/Segregated
Institution/group home
Treated Differently

Charting the LifeCourse | www.lifecoursetools.com
Trajectory Across Life Experiences

Chores and allowance

Dating & Heartaches

Birthday parties with friends

Learning to say “no”

Scouts, 4H, faith groups

Summer jobs, babysitting

Playing sports or an instrument

Making Mistakes

“Anticipatory Guidance for Life Experiences”
Life Experiences = Life Outcomes

Experiences at age 5

Experiences at age 13

Experiences at age 65

What We Want

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

What We DON’T Want
Life Experiences = Dignity of Risk

- Dignity of risk is the right to take risks when engaging in life experiences, and the right to fail in those activities.
- Lack of experiences and over-protection can result in lowered expectations, learned dependency, low self-esteem and underachievement.
FOCUS ON SCHOOL AGE

DAILY LIFE & EMPLOYMENT

It’s important to think about who your child is spending time with and having life experiences that will prepare him/her for life in the future as an adult. Do you have the expectation that your child will be employed as an adult, and what is he/she doing at school, at home and in the community to learn skills to prepare for adult daily life and employment?

- Am I in the least restrictive environment or neighborhood school?
- How am I learning social skills as well as daily living and academic skills in my school experience?
- What are your visions for my future as I learn and grow and are you asking me what I want to be?
- What kind of chores or responsibilities do I have at home, like cleaning my room or picking up my toys?
- How can you organize things differently to better accommodate me, and what routines/strategies might help both of us throughout the day?

COMMUNITY LIVING

Community living is not just about where we live, but about how we are accessing and using it in our communities. Seeking and learning about different kinds of living options will help your child have a better idea of what their options will be when they are an adult. Going places that same age peers go and being involved in neighborhood and community activities will help your child learn to continue to learn and grow.

- Is our home in a school district that promotes inclusive education, so I can learn and grow with my siblings and other neighborhood children?
- How are you helping me learn about different types of living arrangements (e.g., apartments, house, roommate, dorm)?
- What community places, activities, and events do you take me to?
- What adaptations to our home you have explored that would better meet my needs?
- What options for getting to and from school, other than special transportation, have you explored (e.g., regular school bus, carpool, walking to school with other neighborhood children)?

SAFETY & SECURITY

Keeping safe is very important now and for their future safety as adults. You can help them learn to appropriately interact with “helpers” such as police, firefighters and emergency responders, and it’s never too early to begin learning about money.

- Who do I tell if I don’t feel safe or if I am being bullied or victimized?
- How are you helping me learn about stranger danger, and who I can trust?
- How are you keeping local emergency responders up-to-date as my needs change?
- How are you helping me know what to do in an emergency? Do we practice safety drills and have a disaster plan that takes my needs into account?
- How are you learning about and helping me understand my and our family’s rights regarding education?
- How are you helping me to choose to decide how to spend money?

FOCUS ON SCHOOL AGE

SOCIAL & SPIRITUALITY

Building friendships and relationships, leisure activities, personal networks, and faith community

- How am I learning about making friends and maintaining relationships?
- How are you encouraging me to try different activities so I can figure out what I like to do in my free time?
- How can I get involved and be included in extracurricular activities at school, parks and recreation or other community activities where I can meet and make new friends?
- How are you helping me explore spirituality and find a welcoming faith community?
- Am I learning the spiritual values and cultures of our family and participating in the rites and rituals of our faith?

HEALTHY LIVING

Managing and recovering health care and staying well - medical, mental health, behavioral health, developmental, wellness and nutrition

- How are you helping me learn to ask for help or tell someone when I am sick or just don’t feel well?
- What are you doing to teach me to how to greet and interact with doctors and other medical professionals?
- How are you helping me understand my disability or healthcare needs and how it affects me as I grow and change?
- How are you helping me know what is good (healthy foods, sleep, exercise) and bad (drugs, smoking) for my body?
- How am I learning about healthy foods and nutrition and making healthy snacks?

ADVOCACY & ENGAGEMENT

Building valued roles, making choices, setting goals, assuming responsibility and driving how one’s own life is lived

- Are you interested in helping other parents or engaging in policy or systems change?
- How am I being supported to learn leadership skills and take on leadership roles at home, school, or in the community?
- How are you helping me to be part of and start to lead school or person-centered planning meetings?
- Do you present yourself as an expert regarding me and my needs, and how are you helping me learn to be the expert on myself and my needs?
- How am I learning the importance of roles at home, school, and other places?
- How are you helping me find valued roles and chances to help others or give back to the community?
Applying the Principle of Trajectory and Life Experiences
What is the Purpose of Your Trajectory

- Problem solving?
- Working toward broad life goals or specific short-term goals?
- Planning day-to-day activities?
- Being clear about what you want & don’t want?
- Understanding past life experiences that either helped or were barriers to what you wanted?
- Strategic planning or implementation?
Family Perspective Trajectory for Ben

**Charting the LifeCourse Experiences Trajectory**

- **Positive Past Experiences**
  - Being included in school
  - Homecoming King
  - Boy Scouts (eagle)
  - Volunteering
  - HS Diploma
  - Having chores and responsibilities
  - Learning to use his debit card and carry a wallet with ID

- **Goals For the Upcoming Year**

- **Negative Past Experiences**
  - Low expectations of others
  - Lazy or old school staff
  - Physical barriers
  - Health issues - arthritis, scoliosis, osteoporosis
  - Medication side effects
  - Overdependence on paid "helpers" or para in school

- **Risks And Obstacles**

- **Good Life Vision**
  - Family and friend who love and care about him and do stuff with him
  - Stable income - maybe his own business
  - His choice of where he wants to live and with whom
  - Good health
  - Stay fit - work out, play basketball
  - Going to or watching Nascar, WWE, Royals, Chiefs
  - Going to country music concerts
  - Having electronics (ipad, tv, dvr player, cd player)
  - Always have someone to spend his birthday and holidays with
  - Have a good relationship with his brothers, future SIL’s, and nieces/nephews
  - Keep volunteering at the ES Fire Department
  - Active in his church
  - I want him to BE OKAY, to thrive, even after we (Tom and I) are gone

- **What I DON’T WANT**
  - Poor health
  - lonely or sad
  - broke - no money or dependent only on govt funds
  - be alone on holidays or birthday
  - no friends or family that love him or he loves
  - not have access to activities he loves
  - be mistreated or bullied
Ben – Coping with COVID

LIFE TRAJECTORY | EXPLORING

WHAT WE WANT FOR BEN DURING THE COVID19 CRISIS
- Keep busy
- Keep working on fitness while he isn’t able to access his trainer or the community center
- Stay Connected with:
  - Fire department friends
  - Valued staff
  - Family who don’t live with us (especially Matt)
  - St Ann friends
  - Coffee friends & other community acquaintances
- Stay healthy and active
- Dad and Mom stay healthy too
- Keep a positive outlook on life – BE HAPPY

WHAT I DON'T WANT
- Boredom
- Get COVID19 or any other sickness
- Stress and worry
- Ben scared he will get sick
- Ben worried for parent’s health
- S束ures or other diagnosis related health complications
- Sadness
- Missing family and friends
- Gaining weight/out of shape

STAY HEALTHY/ACTIVE
- Walk out doors when it’s nice weather
- Avoid contact with anyone other than Men or Dad (social distancing)
- Get a list of other exercise ideas from Matt and Adam (weights, push ups etc) – use ZOOM
- Clean up the driveway basketball goal
- Healthy but yummy food choices
- Good and frequent hand washing
- Purell
- Wipe down surfaces daily
- Cover coughs and sneezes
- Check temperature regularly

DAILY LIFE/Routine
- Somewhat consistent wake/sleep times
- Shower daily
- Help with housework/cooking/etc daily “schedule” of things to do such as exercise, physical activity, get outdoors, etc

POSSIBLE OBSTACLES/BARRIERS
- Dad still has to work – potential exposure
- COVID19 on the news and other media all the time
- Other people not complying with social distancing
- Cabin Fever is Real
- Grumpy weather/can’t get outside

Vision for What I Want

STAY CONNECTED
- Facetime Matt and other family
- Skype or Facetime Fire Dept shifts
- Make an encouraging video for ESTD
- Help Ben get on Facebook daily and ‘like’ or comment on friends posts
- Online church services on Sundays
- Front yard 100 day project meet up with Steve

STAY BUSY/NOT BORED
- iPad (WWF, music)
- Remote control truck
- “see stay connected”
- Golf in basement
- Family Movie time
- Explore e-books

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Trajectory Examples from MN Families
## Buying a Home

### Life Trajectory Worksheet

**Past Life Experiences**
- Always had income
- Great neighbors and family and friends
- Room for everyone
- Learned housekeeping basic maintenance
- Make good use of small spaces

**Future Life Experiences**
- Live our community
- Employed
- Follow budget include $ for updates, repairs
- Home warranty
- Make a space our own

**Past life experiences that pushed the arrow toward things you don’t want.**
- Rented more than owned
- Divorce (depending on other’s income)
- Crazy competitive market

**Life experiences to avoid because they push you toward things you don’t want.**
- Continue renting
- Getting in over my head
- Money pits
- Pushed into quick decisions

**What I DON’T Want**
- Smoke smell
- Major structural issues “bad bones”
- Outdated everywhere
- Mechanicals
- Roof
- Other
- High maintenance items
- Pools, hot tubs
- Giant home or yard

**Vision for a Good Life**
- Close to friends, family, school and current community
- Affordable payment
- Sunny spaces for winter
- Workable kitchen
- Spaces for isolation/privacy
- Spaces for connection
- Outdoor space where kids can play unsupervised safely
- Full sized bath tub
- Circular flow
- Potential for personalizing spaces
Kelli

**Past Life Experiences**
- Valleyfair
- Monster Truck shows
- Swimming at the YMCA
- Camping
- Hiking in the woods
- Walking with his dog
- Qualified staff
- Relationship with older sister
- Tubing at Powderidge

**Future Life Experiences**
- Using AG device
- Engaging with him - puzzles, reading books
- Work on ADL
- Going on car rides
- ABA Program
- Continue to work on sensory challenges

**What I DON'T Want**
- In a poorly staffed group home
- On tablets all day long
- Aggression
- Poor hygiene/stinky/unkept
- To be unsupervised if still challenged with safety awareness
- Siblings to neglect him
- Inexperienced staff working with him (abuse/neglect)
- Overly medicated/combative

**What I DO Want**
- LIST what you want your "good life" to look like...
  - Going to Valleyfair regularly in the summer
  - Spending time with family
  - Have a job that he likes (activity out of the house on a daily basis)
  - Have good health
  - Have physical activity daily
  - Good hygiene - dentist appointment/ears cleaned
  - Go on vacation with family
  - Be able to handle change appropriately
  - Less observant with things
  - Consistent daily routine
  - Swimming weekly
  - Sensory activities - compression/spinning
  - Diet - more variety
  - Go out to eat
  - Service Dog
  - Him to be happy & laugh
  - Access to books/library
  - Progress with reading and writing (never stop learning)
  - Physician who understands relationship
  - Nice clothes

**Vision for a Good Life**
- In a variety of activities in the community
- Spending time with family
- Have a job that he likes (activity out of the house on a daily basis)
- Have good health
- Have physical activity daily
- Good hygiene - dentist appointment/ears cleaned
- Go on vacation with family
- Be able to handle change appropriately
- Less observant with things
- Consistent daily routine
- Swimming weekly
- Sensory activities - compression/spinning
- Diet - more variety
- Go out to eat
- Service Dog
- Him to be happy & laugh
- Access to books/library
- Progress with reading and writing (never stop learning)
- Physician who understands relationship
- Nice clothes
Other Trajectories
Reminder: Things to Consider When Developing a Trajectory

• The purpose of the trajectory worksheet
• The impact of life experiences on the trajectory
• The message are you trying to convey with your trajectory; what you are trying to impact/organize/plan?
QUESTIONS?