The Inclusion Notebook
Problem solving in the classroom and community

INTEGRATING LIFE COURSE TOOLS WITH OTHER ESSENTIAL ELEMENTS OF SCHOOL TO ADULT TRANSITION

This TIN describes a 4-session intensive learning opportunity the UConn UCEDD developed for families that incorporates LifeCourse principles and tools with information about exciting initiatives in our state and evidence-based practices concerning school to adult transition.

In this issue, we address non-negotiable realities and values underlying the training, the LifeCourse tools developed by the University of Missouri at Kansas City (UMKC) we use to help families create multi-purpose transition portfolios, and how other transition information is integrated with LifeCourse. The ultimate goal is for families and students to develop a Transition Portfolio which empowers them to take the reins during the transition years to assure as seamless a transition as possible to adulthood once eligibility for school-based services ends.

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The Transition Portfolio

A multi-purpose transition portfolio is developed by every family for their “student” (even though some have already aged out of school services).

The Portfolio contains:
- Core Transition Skills for reference
- Abbreviations for reference
- My One-page LifeCourse Profile
- My Life Trajectory Worksheet with the Vision for My Future
- My Community Resource Map
- My Circles of Support
- My Associational Map of organizations, groups, or clubs I can join
- “75 Action that Build Community”
- My Chart for Exploring Life Outcomes
- My Overall Integrated Services Star
- My Integrated Services Star for Health
- My Integrated Services Star for Employment/Post-secondary education
- Buckets of Support for My Family
- Sample IEP goals/objectives
- Action Plans
- Other POSITIVE student “about me” information (e.g., letters of reference)

Note that what is absent from the Transition Portfolio are evaluations, IEPs, progress notes and similar documents.

Non-Negotiable Understandings

Non-negotiable understandings reflect the values and realities of the adult service world. They are:

Adult services are different from school-based services. Specifically, adult services:
- Are NOT an entitlement (v. school-based services which are),
- Are NOT guaranteed,
- Have different eligibility requirements,
- Have limited funding if funding is available at all -- there may be waitlists), and
- There is no single point of entry.

Percent of eligible people receiving IDEA-funded services (100%)

Percent of eligible people not receiving any adult services (about 2/3)

Percent of eligible people actually receiving adult services (about 1/3)
Time is precious. **Three years is not a long time.** A repetitious theme for participants is “Don’t waste those last years!” of school-funded transition services by insisting on more high-school-like academic instruction at the expense of the student learning functional skills and having real opportunities to facilitate optimal independence, make connections with important others, be able to self-advocate, and so on for full successful adult membership in their communities. The transition years also provide a window of opportunity in which everyone can identify and put into place ongoing supports families and students may need as adults.

**Human services build walls around those they are meant to help.** Another non-negotiable is that “all people have the right to live, love, work, play and pursue their life aspirations in their community (UMKC).” In the training, we use the LifeCourse graphic of “Real People, Real Lives” to demonstrate how we, as “professionals” inadvertently created barriers between the individual, their family, and the community by presuming expertise that is costly and really hard to individualize and use flexibly.

The stars on the third concentric circle image are an exciting reconceptualization of services and support because families, which learn later these are “Integrated Service and Support Stars,” see services and supports can be scattered; are of different sizes to reflect varying intensities, duration, and frequencies according to their student’s individual needs; and flexible, meaning they can fade altogether or be introduced or re-introduced as their student’s needs develop and change. In other words, we desire a system – and these families are pioneers -- where people get the support they need when they need it. It is a very different service model than “one size fits none.”
Use only a Strengths-Based Person-Centered approach. Another non-negotiable is that we only allow use of a Strengths-Based Person-Centered approach. No deficit thinking (i.e., what their student can’t, won’t, or will never do) is allowed. Families are assisted in reframing such statements as “cannot get dressed independently” to “can get dressed with assistance.” We reinforce that these strengths-based, person-centered principles have been around for more than 30 years and do lead to meaningful life outcomes.

Self-Advocacy and Self-Determination are critical concepts. We also include self-advocacy and self-determination (i.e., “Nothing about us without us”) as a non-negotiable. This is so it is not just the families making the decisions for their students. ALL transitioning students have a right to discover what opportunities are out there, to have dignity of risk in making and learning from their mistakes, and to lead self-determined lives that are satisfying as THEY, not their families, define it. Often, this is the first time families have really been encouraged to partner WITH their students so both can take the lead in advocating to school staff what the individual transition program should be.

Connecticut Core Transition Skills

The Connecticut Transition Community of Practice (TCoP) developed 16 Core Transition Skills or skill clusters which were revised in 2016. We have found that, as written by the TCoP, they seem to imply that everyone has to demonstrate each skill or skill cluster totally independently before leaving school. As a result, both families and school staffs can mistakenly determine that a student shouldn’t even try to learn the skill with accommodations like assistive technology as needed and don’t give thought to how the student will fare in each skill area as an adult if they truly may need continued supports.

The TCoP 2016 version says, “Can responsibly perform home activities necessary for survival (e.g., food prep, med management).” We added “with assistive technology and the minimum amount of support needed” to the end of this standard. Another standard of the TCoP 2016 version, “Can demonstrate skills needed to access appropriate transportation (both public and private).” Our rewording applies to all, i.e., “Has access to reliable transportation (e.g., public, ride services, carpooling, etc.) when needed.”
Valued Life Outcomes

Valued Life Outcomes are why the core skills coupled with seamless access to essential adult supports when school services are over is so important. Valued outcomes are the same things families want for their students without disabilities.

These include family, a place of one’s own to call home, friends, spending money, enjoyable leisure time, experiencing success, having human rights respected, being worthy of the journey, not having someone else hold those rights, having diversity celebrated, and giving back to the community.

For valued life outcomes to occur, families are encouraged to have high expectations but are assured this does not mean unrealistic expectations. Another term for this is “Dignity of Risk” (Perske, 1972) in that there is dignity for all young people in making non-life-ruining poor choices or mistakes and learning from them.

One-Page LifeCourse Profile

Family training participants are led through creating a One-Page LifeCourse Profile, a form developed by UMKC. The top blue box is for listing “What people admire about me/My strengths.” The green box is for listing “What’s important to me (my preferences, interests, passions).” The orange box is for listing “How best to support me.” We added the pink column because of our crisis-informed work with individuals who have triggers to avoid and those who really need certain supports. What might not work, as examples, are “raising your voice to me” or “expecting me to read and understand important information on my own” because the student really has difficulty with print.
**LifeCourse Trajectory**

Next, participants complete the LifeCourse Trajectory starting with the vision for the student’s future followed by what is not desired in the future. The vision reflects individualized statements about the Valued Life Outcomes. What is not desired is often the opposite but may also have other specific situations the family and student wish to avoid. Next, they complete the rest of the form – left to right. The furthest left column is where to list previous life experiences in the upper part that form the basis of the trajectory of the student toward the vision for the student’s future. The lower portion identifies previous life experiences that actually aim the student toward what is not desired. The top portion of the middle column identifies what needs to happen to continue the student’s trajectory toward the vision. The lower portion of the middle column identifies what needs to be avoided because its trajectory is toward what is not wanted.

Between sessions, the assignment for family trainees is, with their student, to add to the profile or, if necessary, replace anything they put on the trajectory with what their student says. For example, a parent may envision “A part-time job bagging at a grocery store” but their student may want a full-time job in the automotive field. Disconnects like this lets us remind participants what was already identified as interests (such as cars) in the profile needs to be considered in transition planning because this is how to build a quality future on present assets.

**Social Capital**

An important section of the training is on Social Capital because we know that “…social relations have productive benefits…” and that well-intentioned professional services, as shown in the graphic on page 3, often severe existing family ties and prevent development of new ones for all.

In small groups, participants complete a modified version of community mapping (Crane & Skinner, 2013) using a **Community Resource Map** like the one shown on the right. This allows them to identify in the first column community resources — i.e., “What I want/need.” Examples are health care, fun things to do, emergency services, etc. The second column is for “What’s available nearby?” The third column is for “How can I get there or otherwise access it?”
Two circles of support are created—one for the present and one on which participants list people they hadn’t thought of involving previously. The three concentric circles are the blue innermost circle (intimate & reciprocal relationships), the green second circle (regular friendly contact), and the pink outer circle (casual contacts). The “Y” which splits the circles into three segments each. The top segment is for family members, the left segment is for friends and other social connections, and the right segment is for people paid to be in the student’s life (e.g., doctors, mentors, teachers past and present). The point of the exercise is to develop a well-rounded circle instead of what typically appears for students with disabilities: a few close family members, no one in the blue section for friends, and many representatives in the “paid to be there” third.

John McKnight’s associalional map allows participants to list specific entities in their community that align with their student’s profile (shown below). John O’Brien’s checklist of 75 actions that build community (at the top of page 8) is completed to show what families start doing immediately to build social capital for themselves and their students. Between sessions of the training, participants are asked to commit to, and report back on, what they’ve actually done between sessions to build social capital for themselves and their students.

<table>
<thead>
<tr>
<th>Associations (examples)</th>
<th>Your Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Artistic Organizations</td>
<td>Local government, school, newspaper, local access cable TV.</td>
</tr>
<tr>
<td>Business Organizations</td>
<td>Men’s groups, mental health, social, educational, vocational.</td>
</tr>
<tr>
<td>Church Groups</td>
<td>Mutual support (self-help groups), alcohol, anonymous, Lake Life League.</td>
</tr>
<tr>
<td>Community Groups</td>
<td>Neighborhood &amp; Black groups, inner circle, community, Churchwomen’s circle.</td>
</tr>
<tr>
<td>Educational Groups</td>
<td>Outreach groups, garden clubs, conservation clubs.</td>
</tr>
<tr>
<td>Political Organizations</td>
<td>Democrats, Republicans, caucuses.</td>
</tr>
<tr>
<td>Professional Groups</td>
<td>Younger groups, young adults, peer support.</td>
</tr>
<tr>
<td>Service Clubs</td>
<td>Service clubs, library, AAMU.</td>
</tr>
<tr>
<td>Social Service Groups</td>
<td>Peace groups, service, advocacy, business.</td>
</tr>
<tr>
<td>Sports Leagues</td>
<td>Bowling, running, baseball, fishing, volleyball.</td>
</tr>
<tr>
<td>Study Groups</td>
<td>Study clubs, book clubs, study groups.</td>
</tr>
<tr>
<td>Veteran’s Groups</td>
<td>Veteran’s groups, Vietnam, Korean, veterans, military.</td>
</tr>
<tr>
<td>Women’s Groups</td>
<td>Women’s groups, national, political, social, educational, vocational.</td>
</tr>
<tr>
<td>Youth Groups</td>
<td>4-H, Future Farmers, 4-H, YMCA.</td>
</tr>
</tbody>
</table>
We have special stand-alone sessions within the overall training program on 1) transition from pediatric to adult health care, 2) Thinking College, and 3) Customized Employment to open their eyes to possibilities. We also have intensive discussions about alternatives to guardianship such as supported decision-making and financial opportunities such as Ticket-to-Work and A.B.L.E. accounts. We cycle back to these topics, as well as the values and realities of adult services, throughout the training so that, when we start Exploring Life Possibilities families are prepared for an onslaught of new information and future options and opportunities they may never have considered before.
Exploring Life Possibilities

The Exploring Life Possibilities table was developed by UMKC to help families think of the myriad of opportunities for their students across life domains. Our UCEDD modified the table in three ways: 1) there are some additional “out-of-the-box options” listed, 2) we deleted terms not used in our state, and 3) the line we put near the bottom of the page separates options below the line that are not consistent with the full community inclusion mandate of the federal Developmental Disabilities and Opportunities Act of 2000.

What is consistent, i.e., those options and opportunities which reflect natural lifestyles in the community and are more innovative, appears above the line.

During the training, we go through each category of life possibilities separately, showing, explaining, and discussing what’s on each list. This COMMUNITY LIVING slide shows “Granny Pods” (or small houses) as an innovative consideration above the line but puts Institutions/Nursing homes, Intermediate Care Facilities, Group Homes, and Special Farms/Separate communities below the line as undesirable for community inclusion.
Integrated Services and Supports Star

When we introduce UMKC’s Integrated Services and Supports Star, participants are led through completion of one star for pediatric to adult health care transition and another star for school to post-secondary employment or education transition. They are supported in completing an additional star of their choosing. The direction for completing the star is, first, identify the student’s assets as related to the star topic. For a student whose vision is working in the automotive industry, for example, some assets might include “knows the makes and models of all cars, domestic and foreign, manufactured since 1950.” Another asset might be “friendly and outgoing” or “hardworking.” Second, relationship-based supports are listed. For this student, it may be that there is a friend of the family who works at a car dealership and a relative who collects model cars. Third, what the student already has or would need to maximize independence is listed under Assistive Technology. Examples might include have apps on a cell phone that allow for reminders about time, emergency health care information, or a video resume. Fourth, families identify community resources that can be accessed. For this student, these may include “gasoline alley” (a local strip of car dealerships), nearby service stations, and a car wash. Lastly, families identify what eligibility-based services and supports the student is likely to need to be successful such as enrolling in the Ticket-to-Work program to manage benefits during initial employment and possibly a job coach through the Bureau of Rehabilitation Services (short-term) or the Department of Developmental Services (long-term) if natural supports within a workplace are insufficient.

The rational for this order is:

- Wanting the student to be as self-sufficient as possible
- With relationship-based instead of paid supports to the maximum extent feasible
- Using whatever assistive technology will result in greater access to all aspects of
- Community Resources and community life.
- Accessing eligibility-based services is not a given like a Free and Appropriate Public Education but rather only to support the above objectives (as with ABLE accounts and Ticket-to-Work) or as a last resort to allow for more equitable distribution of the limited eligibility-based resources available to adults.
Family Buckets

UMKC’s Buckets exercise is a time for family trainees to review the portfolio compiled so far and identify what they need to discover and navigate, with whom they need to connect and network, and what goods and services to explore (specifically technology and community resources). As with the Integrated Services and Supports Stars, they are told to explore eligibility-based supports only to be accessed as the last resort because of the realities of the adult services system.

Completing the Portfolio

Final activities of the training involve putting the touches on the Transition Portfolio which, at this point, contains copies of everything covered so far. The Modified Core Transition skills are revisited so families (hopefully with their students) can identify what the team needs to target as realistic goals and objectives consistent with everything else in the student’s transition portfolio.

Every participant calls out a skill area or cluster from the modified list they feel their student should work on (which may have nothing to do with the curriculum of the transition program they are in) and are supported by UCEDD trainers in publicly brainstorming draft goals and objectives with the group to propose to the team. For the prospective automotive worker, the results-oriented goal for postsecondary employment might be “Makes a final decision about enrolling in an automotive apprenticeship program after meeting the following objectives: (1) Discovers, through tours, job shadowing, and internships, the range of employment opportunities in the automotive field. (2) Completes evaluation sheets, with assistance, assessing the pros and cons perceived in each discovery experience. (3) Participates in an unpaid internship at a car dealership, gas station, or dealership. These sample goals and objectives are placed in the portfolio to be used at the student’s next PPT meeting.
**Action Plans**

Last, all Transition Portfolio components are reviewed through reflection so that participants can complete Action Plans which they are accountable for implementing. Their first Action Plan is written for the month or so between the third and fourth sessions. Their second is written before leaving the fourth session. We follow-up to see how they are doing and are available to provide technical assistance if they run into resistance or need more information for implementation or anything new that grew out of this process. Sometimes, they contact us to share wonderful transition portfolio outcomes -- like their son being included in a college ice hockey team or their daughter being hired by a store she loves because she confidently self-advocated “I’ll do anything except the register because I can’t do math.”

![ACTION PLAN FOR moving forward](image)

**Data from These Trainings**

Satisfaction ratings by participants were collected after each of the four sessions of trainings. Each of three 4-session cohorts (Spring of 2019, Fall of 2019, and Winter of 2020) reported being satisfied or mostly satisfied with the training they received. Pre- and post-assessments also were administered with two post-tests: the first was after the initial three days of training and the second at the conclusion of the 4th and last sessions. Almost all trainees demonstrated improvement in learning between the pre-and post-assessments and sustained that learning for the extended period between the third and fourth sessions. The exception was with the third cohort where negative effects of individual responses concerning transition portfolio contents, health care transition, and employer accommodations caused a drop in the initial post-assessment scores. The second post-assessment brought scores back up to the pre-test level for this group.
Individual follow-up by phone was also conducted for 35 of the participants representing each cohort. Nine were actually contacted and 77 per cent (or seven) of these described their progress in implementing their last action plans. Of the two remaining, one’s circumstances had changed so the students was living elsewhere and the other declined comment.

Following are some of the ways in which respondents reported successful implementation of their transition Action plans:

- facilitate as smooth a values-driven transition from school-based services to adulthood as possible given the realities of the adult service system.
- Inclusion in school productions (more social connections)
- Two students were included in college sports
- Access to Assistive Technology
- Successful transition to adult health care
- Allowed more independence by parents (Dignity of Risk)
- Work experiences instead of summer school
- Accessed to Ticket to Work and a job
- Changed adult service provider to one more focused on the individual’s strengths
- Self-Advocacy (“I want to work for you but I can’t do math so I can’t work on the register but I’ll do anything else”)
- Adult funding became self-directed
- Sought technical assistance from the UCEDD about how to increase success in teaching greater independence in activities of daily living at home.

These results, both quantitative and qualitative, demonstrate the success of this four-session intensive learning opportunity in empowering families and their students to

**Summary**

This Inclusion Notebook describes how the UConn UCEDD incorporated LifeCourse tools into a values-based and realistic transition training. The result is a Transition Portfolio for their student reflecting non-negotiable values and realities about adult services underlying this training, containing LifeCourse tools appropriate for this stage of the student’s life, and putting into one place other transition materials are integrated into the Transition Portfolios.
Resources to Explore
(and sources of forms contained in this Newsletter)

- ABLE Accounts https://www.able-now.com/
- McKnight, J. Abundant Community. https://www.abundantcommunity.com/
- Self-Advocacy Resource and Technical Assistance Center https://selfadvocacyinfo.org/
- Think College National Coordinating Center. https://thinkcollege.net/
- Transition to Adult Health Care. https://uconnucedd.org/projects/adult-healthcare/
- Workforce Innovation Technical Assistance Center http://www.wintac.org/

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