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**Healthy & Ready to Work MODELS**  
**Telephone Script**  
*November 19, 2007*

Thank you for agreeing to be interviewed. Healthy and Ready to Work (HRTW) colleagues have suggested that your program has been successful addressing the many complex issues confronting children and youth with special needs planning for transition. There may be components in your program suitable for replication in other settings.

I work at John Snow, Inc. (JSI), an international public health consulting company headquartered in Boston, contracted by the federal Maternal and Child Health Bureau's Division of Services for Children with Special Healthcare Needs to identify and understand these various components. I have a series of questions; your answers, and nine other programs' answers, will be summarized in a report, along with recommendations, submitted to the Division. This phone call interview should take approximately one hour to complete. Again, thank you in advance for your time. Any questions before we begin?

Over the course of many discussions with project officers at the Division of Services for Children with Special Healthcare Needs and key leaders in the field, we have concluded that a comprehensive HRTW program always addresses more than one component of transition. In addition to answering the questions related to each, I hope you will comment further when you can.

**I. Physical structure/facility** where your program is set up and where you provide services:

*Please describe:*

a) physical structure of your facility (freestanding clinic, hospital-based, telephone information only, etc.)

\_\_\_\_\_

b) Do you receive any funding from MCHB or your state Title V program?

\_\_\_\_\_

c) location (urban/suburban/rural/frontier, centrally located, on a bus line, near a hospital, school, etc.)

\_\_\_\_\_

d) hours of operation \_\_\_\_\_

e) Are the program physicians and/or transition coordinators available to patients by e-mail?

\_\_\_\_\_

f) other comment \_\_\_\_\_

## II. Staffing

a) Do you have a staff position dedicated specifically to coordinating transition activities?  
YES or NO

b) If yes, please explain the level of effort (full-time vs. part-time)

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c) other comment

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## III. Medical Home

*The following questions are an attempt to understand the extent to which you have standardized your office practices. If you answer "yes" to any of the following questions, please describe further.*

a) Does your practice have a written transition policy posted?

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b) Does your practice conduct annual assessments that include transition elements such as health care management, patient's level of independence, and benefits coordination with adult services?

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c) Does your office prepare medical and other evidence documentation for disability determination required by adult services?

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d) Do you discuss transition after diagnosis?

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e) How soon after diagnosis, do you introduce the youth/family to some/all of the following: 1) preparing for adulthood, 2) life span skills to increase health care management, 3) identifying a larger circle of support for those children who will require greater level of adult supports as they age to adulthood, and 4) other?

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f) At what age of the child do you prepare her/his family that she/he can be seen by the doctor alone (without parents in the room)? \_\_\_\_ At what age do you target to see patients alone for some or all of the encounter time? \_\_\_\_\_

g) What key elements are included in a health care transition plan?  
(These could include 1) maintaining health care after age 18, applying for benefits (vocational rehabilitation, supplemental security income (SSI), other ways to increase health care management.)

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h) Do you create an individualized health transition plan?

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i) At what age do you begin planning for transition preparation with youth and their families?

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j) How are referrals to adult specialists made (for example, does the transition coordinator or pediatric specialist usually do this)?

---

k) Do you provide support and confer with adult providers post-transfer? YES or NO

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l) If yes, are these consultations reimbursed?

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m) Do you actively recruit adult primary care/specialty providers for referral?

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n) Do you provide any educational packets or handouts on transition as part of the plan? \_\_\_\_ If yes, how old is the patient when given these materials? \_\_\_\_

o) Do you assist family/youth in creating a portable medical summary? YES or NO  
If yes, what methods do you have in place to do so?

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p) Do you assist in planning for school/work accommodations? YES or NO  
If yes, what methods do you have in place to do so?

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q) Does your practice assist in developing health care and accommodation plans for IEPs or work plans? (Is this done offsite or via phone calls, e-mails? Draft plans shared?)

---

r) Do you refer family/youth to any of the following resources that support skills-building: mentoring, camps, recreation, activities of daily living, volunteer/paid work experience?

---

*The following may be issues/considerations that you have addressed at your program/practice. I'm going to run through the list. Please stop me and comment when appropriate.*

s) Do you:

teach children/youth and their families to know the health and wellness baseline

---

teach children/youth how to give a concise medical report to new providers

---

develop a plan to respond to medical emergency/ cy knows warning health signals

---

train staff to support youth when they call in to make their own appointment

---

discuss how to maintain health care coverage (public and private) prior to age 18

---

encourage patients to ask their own questions and provide status reports to new providers/practices

---

give youth/families a copy of discharge summaries, medical test results, and select physician reports that may be needed later to document disability for adult services

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s) other comment

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#### **IV. Financing/Insurance**

a) How often are you requested to provide additional medical and other evidence/documentation to obtain services, maintain benefits, or pay for durable medical equipment?

---

b) Has your practice developed a tool or form to assist in developing this type of medical summary? YES or NO

If yes, would you be willing to share this tool (or any other tools or forms with the Division?

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c) Does your practice provide samples of successful documentation to care coordinators? \_\_\_\_\_ to families? \_\_\_\_\_

d) What methods do you use to stay updated about state mandated and other insurance benefits for youth after age 18?

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e) Who in your office is charged with staying current on health care insurance changes (public and private, state mandates)? \_\_\_\_\_ How are these updates shared with your staff, shared with youth and their families?

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f) Do you have any processes in place to disseminate this information to the families of CSHCN (such as in the waiting area and during the encounter, do you make information and updates available to families)?

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g) If time and money were not issues, what other guidance could you offer to help youth and families prepare for transition to adulthood?

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**V. Other components**

*Please provide as much detail as possible when answering the following questions. In order to recommend replication of any of these components, the Division of Services for Children with Special Healthcare Needs will need complete information.*

a) Has your program established a family advisory committee or youth advisory committee? If yes, explain its structure and impact.

---

b) Does your program work with local bus or van companies to coordinate transportation for clients to and from appointments? YES or NO

c) If yes, is this service just for Medicaid patients?

---

d) At what age of child/youth does your practice/program encourage patients to:  
volunteer \_\_\_\_  
begin work experiences \_\_\_\_  
discuss post secondary options when appropriate \_\_\_\_  
seek employment opportunities \_\_\_\_

---

e) What do you think your program/practice does especially well in regards to preparation for health care transition?

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g) Where does your program/practice need to improve regarding preparing for health care transition?

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h) Are there any “essentials” you would coach other transition programs/ practices to include? (In other words, what do you think makes a successful transition plan? What couldn’t you do without?)

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Please elaborate on anything else that you think makes your program/practice a model one.

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i) Do you know of other practices in your area or nationally that are also doing good work in transition?

## **Healthy & Ready to Work MODELS Project**

### *Helpful Links*

#### **Guidelines For Adolescent Preventive Services (GAPS) materials**

<http://www.ama-assn.org/ama/upload/mm/39/gapsmono.pdf>

#### **Guidelines for Health Supervision of Infants, Children, and Adolescents (2<sup>nd</sup> edition)**

<http://www.brightfutures.org/bf2/pdf/>

#### **Guide to Clinical Preventive Services, 2007 Recommendations of the U.S. Preventive Services Task Force**

<http://www.ahrq.gov/clinic/pocketgd.htm>

#### **Gillette Lifetime Specialty Healthcare**

<http://www.gillettechildrens.org/default.cfm?PID=1.3.8>

#### **Waisman Center Wisconsin Healthy and Ready to Work Project**

<http://www.waisman.wisc.edu/hrtw/Publications.html>

#### **Waisman Center Children with Special Health Care Needs, Health and the IEP**

<http://www.waisman.wisc.edu/cshcn/cdrom.htm>

**Healthy & Ready to Work MODELS Project**  
*Interview with Florida program - JaxHATS*  
*Interview conducted on January 16, 2008*

**Background**

2004 - Pediatrician leaders/leaders of children's health services, leaders of title V program, etc agreed on transition and mental health as major issues. (Did multi group voting, people brainstormed and vote and top ones were transition and mental health)

Down syndrome association, Hope Haven does a lot of therapies/work with mentally complex children.

Children's hospital that is part of larger hospital network (Baptist network). Children's Medical services/Title V also did a lot of planning. When looked at literature, there wasn't a lot on transition, but looked at policy statements from American Academy, Center for Adolescent Med (?)

Put forth proposal to CMS/Title V. Almost all of them were disease specific transition models. Appreciated that, but wanted a transition program that was NOT disease specific.

Jacksonville a billion people, lot of rural areas, don't have luxury of focusing on program on spina bifida, etc. don't have volume to sustain that. Wanted to do transition program to address multiple conditions. General chronic disease model.

Talked with John Reiss how to organize, he identified Minneapolis, Cincinnati, Baltimore, Los Angeles, etc. thought could bring in ideas. Appreciated Ronna Linroth's input. Cincinnati – Tom Webb, very modest about what he had done. Focused on developmental disabilities.

Los Angeles – chronic disease

Baltimore – Spina Bifida

Minneapolis – CP / Gillette neuron-muscular

**Transition Program - Funding**

Started with first patients in December 2005 at ambulatory care center, part of U of FL

Plus or minus 220 patients.

We funded the planning process with staff support from other projects.

To hire for dedicated staff, used funding from Title V programs from December to June. Started with that contract and going year to year. Proposed program as a pilot – had to see certain number of patients, collect evaluation data, etc. Viewed as start up. Didn't go to outside funding, were able to get it from the state which limited from year to year.

Six month period = \$180,000

Current annual funding = \$300,000

Covers 40% me

15-20% internist partner – Dr. Edwards who has in hospital responsibilities

Part time clinical social worker, part time administrator – full 40 hrs. – Paulette Danielle

Full time admin assistant

AmeriCorps volunteer 40 weeks/year

Doesn't include clinical staff i.e. med assist, finance/billing people, receptionist, etc. not covered in \$300,000 grant money. Hospital essentially donating the money – we get the clinic space and clinic support services for free. Losing money on us, but they are very supportive.

### Space

Ambulatory care center is big -- five or six stories

First floor is general internal med, outpatient care. Also has specialists that we interact with regularly (i.e. can talk to endocrinologists across the hall)

\*\*\* one of the big problems with transition care is that everyone (all pediatricians) are for it. But on the adult side, the ones that need the transition support are most complex. Majority have lousy insurance, depending on the state, many are uninsured.

\*\*\*All the work in transition should be on **adult side**. It's good to work on ped side so have good hand off to adult, but all work has to be on adult side.

Dr. Edwards has gone to bat, has built good relationships, etc.

(Have been invited to go on rounds twice, connection with internal medicine.)

Dumb luck that they are in good location/position they are in.

\*\*\*Absolutely key thing is that don't necessarily have to be next to the specialist, but need to get into their system and be seen in their system. So that when make referrals, comes from internal clinic. Get it like they would get any other adult referral. Start to treat you like one of their customers. Specialists have been great at getting back to them, educate them about transition, most are very intrigued by it. Get word out by infiltrating their system.

\*\*\*Really hard if transition located in pediatric setting because hard to get into adult system and influence that system.

### Transition Program

Program is 16-25year olds. Sometimes fudge on 25yr because sometimes older developmentally disabled, make exceptions to transition them.

Perception from families – do they like coming to ambulatory care center with specialists?

- “less than ideal because now youngest in the waiting room” – most are elderly – 60 – 70 verses in pediatric, they were the oldest

\*\*\*Ideal program = integrated in adult world, but more specific youth emergent adult clinic

Have kicked that idea around, and now that getting known to adult services, we could leave the space and still have a good relationship with internal medicine.

\*\*\*Invaluable to develop relationships, make referrals that stick better, are accommodating.

Biggest thing in transition is making system work better, create linkages in pediatric and adult specialty services – more systems rather than patient focused

Being in adult space very helpful.

Helpful as pediatrician – people needing transition have complicated diseases, having both internists and pediatrician in clinic is great. Have been able to bring in mix of medical expertise for the complicated situations.

### **Physical Structure/Schedule**

Exam rooms accommodate wheelchairs. One quarter patients in wheelchair, have wheelchair weighing station.

No tables that go up and down.

20 year old clinic so physical space is not optimal, but isn't bad.

See patients all day Tuesday and Thursday morning. Started clinics at one half day a week, now up to three half days.

Were only given two morning slots, had to be for afternoon. As expand, want to get more afternoons so youth don't have to miss school.

How are youth finding you?

“our referral base has several different courses”

Largest is title V itself – CMS. 4,000 enrolled in this area. Generally 16 years old and above, although doesn't mean not talking to them before that. May get new clients 17 yrs or 18 yrs.

Second biggest – Morris (?) pediatric clinic. Have 120 pediatric specialists, all major specialty areas. Were part of planning from beginning. Trying to develop a “pre-transition”.

\*\*\*A lot boils down to relationship building – hematology/oncology. Neurology/neurosurgery. Met with them, asked what kind of patients you transition.

**We are a primary care, medical home program. Enhanced chronic care model.** Wagner model is better than MCHB medical home.

We are trying to make sure referral works, etc. We will see them as frequently as we need to. We will see them, want to know specialists will do as good a job as they have done with them.

“Why don't we get together with adult specialist and talk about your concerns.”

Morris has rule about cutting people off by age. Want to make sure we are letting them go in a good place. Open communication between ped spec and adult spec.

There are more adult specialists than pediatric specialists.

University only place that takes Medicaid.

Clinic located in poor neighborhood. Establishing satellite clinic in better part of town for private paid patients.

1/2-2/3 medicaid and 1/2 - 2/3 are private insurance.

We will take them as primary care, and then refer to specialist

1/3 patients are complex, and private sector can't provide coordinated care.

### **Transition Plan**

Process is very simple referral form (otherwise they wouldn't complete elaborate one)

Hematologists – for cycle cell, worked on care plan. More physician components of care plan, and send to JaxHats. They will call JaxHats who will request as much info as possible. Will send out docs for patients to sign to release records to get as much as possible before hand. We have electronic medical record. Basically a problem oriented care plan.

### **Intake**

Risk factor, screening

Transition assessment readiness tool – very far from figuring it out. 42 item questionnaire. We took all the tools we could find from colleagues around the country, compiled, looked at them, some of them knowledge items, some behavior. Narrowed down to 60. Asked “do you do this” as opposed to also “do you know how” to narrow down. That would make sense to us, have health education psychologist, work with John Reiss, how do you measure where people are at in the transition process, financing, economics, etc.

Disease specific self management issues.

At intake – bring them in to clinic, get to know them, two visit process. Fill out GAPS – general adolescent preventive services. Parents filled out one, youth/adolescent fills out the other. Basically asks them about their health problems, medications, concerns, etc. 60 questions on risk behavior, sexuality, drinking, drugs, eating disorders, etc. Surprised by how honest they are. Send to home and ask them to fill it out.

Over half are 18 so can talk to them without their parents, but not often an issue.

95-98% say “lets talk about sex with mom here”

A few patients keep things confidential. Practically speaking hasn't been an issue.

Review records before second visit. At second visit, develop a plan similar to primary care “care plan.” Preventive care, disease specific care, contraception, disease prevention, sexuality, etc.

Then get into general transition.

Deborah – social worker takes care of non medical. Asks about career goals, independent living goals, etc. We have used transition assessment tool, make notes re: referrals.

Junior college, voc rehab link.

Trying to get link with Duval county and their transition clinic. But don't have funding yet.

For any given condition, there are specific services to be referred to. Get actively involved in identifying life goals, living goals, education/vocational goals.

All scrips – electronic medical record, IT people willing to develop a care plan to put into information system. Still working on developing form for providers and form that 16 year old can have. Transition form we use to assess them – clinically where are you in being independent, role in healthcare system, edu/voc issues. We use tool clinically. They fill it out, we look at scores, to see areas you need to work on.

Every three – six months have a team meeting, review people we think are ready. Will try to do transition questionnaire every six months. Score them and look at their scores. If scoring high, realistically, then we graduate them from our program and plug them into primary care beyond transition program.

Are they doing what they need to do, keeping appointments, not dependent on parent, arranging own appointments. Then go somewhere within U of FL system. Big navy town so have people who just move away.

Everyone on board with concept. Try and get everything as organized possible before we do transfer them so don't get overwhelmed by new problems, new referrals, etc. In same electronic medical record they can review all our notes.

Funding year to year \$300,000. Non recurring funding. A couple of legislators who are tremendously supportive.

This year trying for more funding for JaxHats.

This bill would give \$650,000 to expand to 500-600 patients and also recurring funding, which now currently don't have.

Morris reluctant to give up private pay patients. We have high proportion of Medicaid. Loss of health insurance as huge problem. Between 18-21, Medicaid can carry you in our state. Have 30 patients in that safety net program. When they turn 22, in this county, not covered by anyone. One of big policy issues is extend Title V to 25 – 30.

Medicaid stops at 18. Very limited insurance. Not comprehensive health insurance.

Work hard to get those who qualify on SSI. Many of severely effected youth can get on SSI. If parents insured, help them do paperwork before 18 to demonstrate child dependent.

Indigent Care Program

ER divergent program. We're trying to get funds from hospital, have proposal into them for that.

Work as a team. Paulette Danielle will see them, will ask about insurance, etc. Then we'll advise them and refer. Deborah will also see them, so between all three, hopefully things don't fall through cracks. I focus on clinical issues, they focus on family, insurance, legal issues, etc. Refer them to sources, etc.

Website – John Reiss's books that were developed. The booklets and thinking about transition, give him the credit. In first year, subcontracted him as consultant to help guide us, construct web page, think about intake process, etc. His booklets very good for informational self assessment. Way too long, not great in clinical setting. Trying to get something to use in clinical setting.

### **Advisory committee**

Several patients/youth that participate - 4

Several parents – 4

10 other people who are mostly agencies we work with or leaders in advocacy groups – down syndrome association, ARC

Getting stronger, have had parents come to us, some of group homes seek them out because no where else to go for coordinated care.

Group meets quarterly. Usually bring agenda, upcoming legislation, ask for input, etc. Input on care plan, etc.

No show rate of 30%. Send something in the mail, call at least once, etc. Everyone who didn't show, the day before, said they'd be coming. Tolerate a lot of no show "we'll never give up on you" – part of the stage they're going through, part of why they need transition.

i.e. diabetes, adherent 13-14, then fall apart and come to us. When at the end of it, joy of getting them to move forward, get disease under control, etc. Do things they need to do to get disease under control. When early or mid adolescent, not very compliant, etc. Make every effort – new things come up, organized chaos. Hard to have organized model to move through for assessment. Address transition issues as well.

High no show rate for visits when spend most time with social worker – disease self management, keeping notebook, etc. "coaching" – life skills. Trying to do more where do comprehensive care. Very hard to do forward planning when calling from ER.

\*\*Has to be individualized.

\*\* helps to have model in mind, have specifics.

Want to be able to do it electronically - Look at patients and see how many comprehensive care visits, how many acute, how many transition, etc. Run through list of patients every month or so, see who needs transition visit, etc.

### **Additional comments/Tips**

\*\* team approach

Depends on target population – have medical students and residents in clinic, very complicated – need team approach

\*\* social worker, nurse care coordinator, although makes model expensive

Cultural comp – try to stay on top of it. Before launched website, had youth go through site for feedback. Checked literacy level of transition tool for readability.

Our area is African American and White. Try and arrange interpreters, try and be culturally sensitive. Youth are from poor part of town, pred. African American. No one other than secretary on staff is AA. Have room to grow in that area.

What kind of evaluation practice?

We do an evaluation plan, looking for funding. As routine, formative evaluation, do quarterly checks to see how we're doing with different processes. Patient satisfaction questionnaire have filled out at first visit, and every six months.

Reducing ER visits? All self report, so don't know.

Ask them their rate of ER use, track utilization of referrals.

Try and track outcomes – ask if successfully transitioned to adult services. When we send them away, is it a good send away? Or did they just disappear?

High satisfaction, hospitalization rates problems of small numbers but have shown decrease so might not mean anything. Difficult to measure, episodic by condition.

Absolutely reducing hospitalization so make a difference.

EM comments:

Exciting.

JaxHats – we've learned more in last couple years than whole career

Primary care docs as front line for folks with complicated conditions.

Team of advocates

Not experts, have to take time to look things up, etc.

Jeff Goldegan – pulled together task force for Mental Health, mapping out how system works and doesn't work.

Have dearth of mental health providers.

We see a lot of children with mental health conditions – developmentally disabled. Very common. Out of 200, probably 30-40 co morbid mental health, bi polar, etc. helping manage them with psychologists. Etc.

\*\*\*wouldn't exist without title V.

**Healthy & Ready to Work MODELS Project**  
*Interview with Indiana program - CYACC*  
*Interview conducted on January 22, 2008*

**INDIANA – Indianapolis**

Mary Chicarelli  
Donna Olson  
Nancy Squigonski

**Background**

CYACC – Center for youth and adults with conditions of childhood  
Clinic at Wishard Health Services Primary

All work in Dept Pediatrics

Wishard is county hospital, staffed by faculty of school of medicine

Dept of Ped gives us indirect support

Wishard gives us indirect support

Direct funding from MCHB Indiana Title V, and division of disability aging services

Indiana University Medical Group IUMG Primary Care – company separate from school of  
medicine to run primary care faculty of school of med. Faculty practice group– provide  
administrative structure for billing, medical care support

**Funding**

Indirect funds through: IUMGC

County facility

School of Med

Dollar and grant from grant funding

**CYACC**

CYACC launched in April 2007. Were doing unofficial work before then, program launched  
April 2007. Came from Dyson initiative – CYSHN and children with disabilities. Transition  
from ped to adult as focus.

Wrote Dyson grant 2002-2003. From Dyson, could do focus groups, based on focus groups,  
received money to see patients, began seeing patients starting April 2007.

Flow of Patients – Since October 15, have CYACC in Wishard.

**CYACC – purely consultative model.**

Keep primary care practice separate from consultative model.

## **Transition**

Transition need: through Dyson focus groups – to come up with answers to questions associated with CYSHN and transition in IN

Seeing patients throughout the state to provide consultative services, so as not to exclude families far away. Serving primary care docs throughout the state. **Mission is to serve primary care doctors throughout state.**

Consultative Care Coordination model: both consultation and care coordination in transition process

## **How do people hear about you?**

Now rolling out rather than explosion (want to avoid being a “mecca”)

Most of patients came from IU PC doctors

Now getting touch with Rheumatology, Dev. Ped, GI, Endocrinology -- four places we have done some roll out/academic detailing with.

Families can also self refer – have heard about your program, etc, then contact primary care physician, get referral from them, etc.

One of our community based collaborative, a Parent to Parent network – line of referral Indianapolis resource center for independent living – no shortage of patients.

Given talks a variety of places – grand rounds in dept ped, grand rounds school of med, two staff meetings at IUMG group practice, other work at local community organizations like Indiana down syndrome association, speakers bureau at school of med, talks at local hospitals

Talks discuss services available through CYACC

- consultation/primary care support CYSHN with transition needs
- care coordination service

Might get referral because special healthcare need that physician/family having trouble with –i.e. change in patients status.

Get a lot of people in crisis. Dream is to get kids at 11 or 12 years old and can then plan. Right now kids in crisis mode, need transition immediately.

Have added four physicians since April, not just Mary anymore. Now expanding number of physicians. All four total 0.6 FTE

## **Staff**

Physicians

Full time social worker

Half time parent liaison

Half time community advocate

Two nurses together make up 1.3 fte

Program manager – Donna

Evaluator – Nancy

Clerical .2 FTE  
Donna full time  
Advocate – adult equivalent of P2P support group

### **Process**

Patient calls – Donna or clerical calls back, performs intake. Gather some pre data before patient comes in. Last psych eval, IEP, waiver, case manager notes, whatever you can get your hands on. Send them confirmation of appointment, release of info for IEP and psych evaluation.

Advisory committee:

What do you need from us? Ask family or adult with disability

Warn them that intake visit for first visit will be over 2 hours. Will meet many people, might not have understanding of future yet. Actual planning happens subsequent to that first visit. Regular weekly meetings to prepare for pre conference. Then check into clinic, nurse brings them to room, going to talk to a lot of different people, you are to tell us what you need as day goes on.

### **Intake**

Intake form – comprehensive form, modeled after geriatric assessment form. Each person on team meets with patient and does some portion of the intake and signs off on their page as they do it. Portions done together. Interview also done alone with youth unless non-communicative. Holistic data collection – medical intake of past medical history, past exams, etc. Look at preventive guideline for adolescents, sexuality, school success, activities of daily living, work exp, volunteer exp, social participation, social, legal, family issues, etc. documenting all on comprehensive assessment form. Takes about 2 hours, may do some lab work, might do hearing/vision screening etc. Have them leave with one or two steps i.e. try to take insulin once a day, try to complete this form on your own, finish Medicaid app.

Will be CYACC patient and report to go to provider. We will provide whatever services they need from care coordination perspective. Rate their complexity -

- 1 – excellent self advocates as a unit
- 2 – intermediate
- 3 – can't complete form on their own
- 4 - high need for support

After done intake and give them next step, we have interdisciplinary meeting.  
Health, education employment, independent living/caregivers, social recreation.

We have their goals in the four domains, and what we need to do to achieve that.  
Someone on the team becomes their point person, mails out suggestions, we will be on contact for questions

If no questions, we'll see you again in a year to touch base.

Some young adults with down syndrome have been well plugged into to PC med home, just need tune up, some prescription tune up.

- 1) intake
- 2) comp assessment
- 3) interdisciplinary planning meeting
- 4) distribute plan to patient
- 5) most patients come back in a month, work on what the crisis was. i.e. adherence problems, come back in a month

“pre and post meetings”

for patient that has issues at school, i.e. breakdown in communication

Determine care coordinator based on what they need –  
i.e. if its healthcare financing, find that person with that strength

### **Team**

\*\*\*Need to meet needs of family using expertise of team.

Purposely hired team with different backgrounds. Staff are consumers – most have CYSHN.  
Couldn't be NOT family centered.

### **Patients**

Transition planning starts at point of diagnosis or birth, but we limit ourselves to start transition planning at age 11. We don't close off at upper end, just don't consider them transition if over 50.

75 patients at CYACC. Birth to 22. 50 older than 22. Total = 125.  
Five steps for all 75. Trying to be more efficient, but never quicker than two hours intake.

Others out there in state of IN, have case managers and care coordinators, and service coordinators, different ways that people define someone who coordinates care. BUT TYPICALLY ONLY COORDINATE SERVICES FOR AGENCIES/SERVICES THEY WORK FOR.

\*\*\*CYACC coordinates across agencies. Can invite CC or CM to join family in clinic. Don't want to be a substitute for what is already going on in community.

### **Systems Change**

ID major glitches in system. Work with state agencies to get to them to see what we are seeing and problems across the state.

No other program like CYACC. No transition that crosses disability that works with communities like we do. Others might be specialized for CF or Down Syndrome (thinks that DS ones actually work to get them to talk to CYACC)

\*\*\*No other place looking at transition to adult care.

Building capacity at the community level. Sometimes physicians don't feel as comfortable working with them.

When patients are referred to us from sub specialists at Riley, (Spina bifida, cerebral palsy, down syndrome) patients from all over the state. If don't have primary care doc, we start looking for them with them. Because we train 75% physicians in state, and ped docs in state, I know a lot of people who practice med in the state. We are able to help people find the services. Med-Peds population is less frightened by CYSHN population than the Adult docs.

Health assessment plan – transition plan and portable medical summary of all services being provided – goes to multiple sources, goes to family, primary care doc, and sub specialist who referred them to us

Has pharmacy

Has care coordinator

Has teacher

Has med equip providers name so what needs to be ordered

Will send comprehensive assessment form and what the finished IHAP Individual Health Assessment Plan

### **Evaluation**

Nancy – data collection

Outcomes around state defined transition outcomes, MCHB goals and around HP2010 goals. Still in process of developing baseline and annual survey. Look at changes over time and outcomes. IHP Individual Health Plan. Working on, trying to work on column that has scan-able data collection elements. Using Rich Antonelli's care coordination tool for primary care. Adapted his tool for transition clinic. Have them programmed into hand held devices for data collection, upload to access database.

IHP on everybody.

Care coordination on some.

Survey to be implemented

Picked age 11 – we recognize that people who come to us as young adults, too disabled to leave their home, very hard to get them off the sofa. Confirmed couch potatoes. Evidence from Patience White, that if you want someone to have an employment goal, need to get to them before they start working at age 14. Youth also set in nutritional habits at sixth grade. Improves school performance if target younger children.

\*\*\*Shouldn't wait until kids are middle adolescents. Should start at early adolescence.

\*\*\*Donna – feels very strongly that time of diagnosis is critical, from that point forward, in helping family understand potential/possibility in realistic way from day one.

Patience White

Fully launched but also start up at the same time. Building resources to pass along to families. Building formal and informal community network. Covered in IHAP. We ask people what their hobbies, strengths, etc. are, and might recommend different activities i.e. bowling, square dance, good dentist, etc.

We have an advisory board that meets quarterly. Dept of education, four or five consumers, etc.

Recommends program at Hopkins – health institute (?)

\*\*team approach

\*\*working with community

Helpful docs from HRTW - \*\*adult self help to get to transition

\*\* need better system of peer support

\*\* need better system of helping parents step back

\*\* better system for ped who don't want to let go – will learn from early adopters

(ped pulmonologist and adult gyno – **don't need totally adult care, can mix**) don't believe in a one size fits all program.

\*\*\*If going to be truly patients centered, need to explore and be creative.

Spina bifida pop

Adult primary care

Ped urology care

Can let go as a parent, and still have adult/child talk directly to doctor/pediatrician

Not necessarily who you go to but the way you do it i.e. have child schedule appt. with ped. doctor.

Disagree with programs say that must be transitioned to all adult care by 18 or 21. Not a problem if still meeting everyone's needs and older than that.

**Center For Youth and Adults with Conditions of Childhood**  
**Riley Hospital for Children**  
**702 Barnhill Drive, Rm. 5833**  
**317-278-0061**  
**fax 317-278-7577**  
**cyacc@iupui.edu**

Date of Assessment: \_\_\_\_\_

Name: \_\_\_\_\_ Clarian MRN: \_\_\_\_\_

Wishard MRN: \_\_\_\_\_

DOB: \_\_\_\_\_ Gender:  Male  Female Age: \_\_\_\_\_

Address: \_\_\_\_\_ County: \_\_\_\_\_

\_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Secondary phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Race:  African American  American Indian  Caucasian  Hispanic  Other

Decision Maker: \_\_\_\_\_

Relationship: \_\_\_\_\_

Legal status:  Guardian  Health Care Representative  Power of Attorney  Informal Rep

Primary Caregiver: \_\_\_\_\_

Contact information (if other than above): \_\_\_\_\_

Health Insurance Plan: (Primary) \_\_\_\_\_

Group: \_\_\_\_\_ ID: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

(Secondary) \_\_\_\_\_

Group: \_\_\_\_\_ ID: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Referring physician: \_\_\_\_\_ Contact/Nurse: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_ Fax: \_\_\_\_\_

Reason for referral: \_\_\_\_\_

**Interdisciplinary Comprehensive Assessment:**

CYACC Physician: \_\_\_\_\_

CYACC Care Coordinator: \_\_\_\_\_

Patient/Family Reason for Referral: \_\_\_\_\_  
\_\_\_\_\_

Principal Diagnosis: \_\_\_\_\_

Present History: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Past Medical History:**

Neurologic-		Cardiovascular-
Respiratory-		GI-
GU-		Renal-
Endocrine-		ID-
Rheum/Musculoskeletal-		Heme-
Skin-		ENT-
Ophthal-		Dental-
Psych-		Behavior-

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Hospitalizations:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Surgery:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Procedures:** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Family History:** \_\_\_\_\_  
\_\_\_\_\_

<b>Medications:</b>	<b>Dose</b>	<b>Time Taken</b>	<b>Purpose</b>
1.			
2.			
3.			
4.			
5.			
6.			
7.			

Allergies: \_\_\_\_\_

Preferred Pharmacy: \_\_\_\_\_ Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

**Health Care Providers:**

Primary Care: \_\_\_\_\_

Contact Information: \_\_\_\_\_

Dental: \_\_\_\_\_ Phone: \_\_\_\_\_

Eye: \_\_\_\_\_ Phone: \_\_\_\_\_

Hearing: \_\_\_\_\_ Phone: \_\_\_\_\_

Psych/Behavior: \_\_\_\_\_ Phone: \_\_\_\_\_

Specialists: \_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_ Phone: \_\_\_\_\_

\_\_\_\_\_ Phone: \_\_\_\_\_

Current adaptive equipment: \_\_\_\_\_

Equipment needs: \_\_\_\_\_

**Services Providers:**

DME Contact: \_\_\_\_\_

Home Care Contact: \_\_\_\_\_

Community Agency Contact: \_\_\_\_\_

Therapy Contact: \_\_\_\_\_

**Immunizations:**

Influenza: \_\_\_\_\_

Pneumovax: \_\_\_\_\_

Tetanus: \_\_\_\_\_

HPV: \_\_\_\_\_

Meningococcus: \_\_\_\_\_

Hep B: \_\_\_\_\_

**Review of Symptoms**

General: fever, chills, weakness, fatigue, weight gain, weight loss

- Normal       As noted       Deferred
- 

Cardiovascular: chest pain, dyspnea, orthopnea, palpitations, syncope, dizziness

- Normal       As noted       Deferred
- 

Respiratory: cough, wheeze, snoring, nasal congestion, allergy symptoms

- Normal       As noted       Deferred
- 

Gastrointestinal – difficulty swallowing, abdominal pain, nausea, heartburn, vomiting, diarrhea, blood in stool, difficulty eating, constipation, fecal incontinence

- Normal       As noted       Deferred
- 

Nutrition – eats 2/3 meals/day, fruit and vegetables >5 servings, milk >2 servings, sweets and fats limited, beverages low calorie

- Normal       As noted       Deferred
- 

Genitourinary – dysuria, frequency, urinary incontinence, discharge, sexual concerns

- Normal       As noted       Deferred
- 

Musculoskeletal – pain, limited movement, contracture, swelling

- Normal       As noted       Deferred
- 

Skin – rashes, wounds, stoma site problem, dryness, calluses, nail problems

- Normal       As noted       Deferred
- 

Neurologic – headaches, focal weakness, numbness, spasticity, seizures, movement problems, falls

- Normal       As noted       Deferred
- 

Vision/hearing/Dental – difficulty with vision, or hearing, dental problem

Dental exam: \_\_\_\_\_ Eye exam: \_\_\_\_\_ Hearing exam: \_\_\_\_\_

- Normal       As noted       Deferred
- 

Cognition – memory problem, concentration problem, expressive disorder, comprehension disorder

- Normal       As noted       Deferred
- 

Behavior – sadness, depression, suicidal thoughts, withdrawal, agitation, aggression, anxiety, confusion, uncooperativeness, hallucinations, wandering

- Normal       As noted       Deferred
-

**Social History:**

Family Unit: \_\_\_\_\_

Individuals residing in home: \_\_\_\_\_

Caregiver concerns: \_\_\_\_\_

Source/frequency of respite from each other: \_\_\_\_\_

Home access: \_\_\_\_\_  Own  Rent

Future living goal: \_\_\_\_\_

**Functional Assessment:**

ADL	Independent	Assistance	Dependent	Comments
Telephone				
Transportation				
Shopping				
Meal prep				
Housework				
Managing money				
Bathing				
Dressing				
Toileting				
Transfer				
Feeding				
Taking medicines				
Refilling medicines				
Managing health insurance issues				
Recognizing signs of illness				
Making doctor's appt.				
Understanding medical conditions				
Making health care decisions				

Future self-care goal: \_\_\_\_\_

Education: Level: \_\_\_\_\_ School/District: \_\_\_\_\_ Contact: \_\_\_\_\_

Adaptive educational services: \_\_\_\_\_  IEP  504

Future education goal: \_\_\_\_\_  
Employer: \_\_\_\_\_ Contact: \_\_\_\_\_  
Support services: \_\_\_\_\_ Contact: \_\_\_\_\_  
Previous experience/volunteer: \_\_\_\_\_  
Future employment goal: \_\_\_\_\_

**Activities:**

Hobbies/interests: \_\_\_\_\_  
Circle of friends: \_\_\_\_\_  
Religion: \_\_\_\_\_ Congregation: \_\_\_\_\_

Self-perceived strengths: \_\_\_\_\_  
Stress management skill set: \_\_\_\_\_  
Estimate of coercive risk: \_\_\_\_\_  Risky behavior  Victimization  
Future recreation/social goal: \_\_\_\_\_

**Legal:**  Independent  Dependent  
Power of Attorney: \_\_\_\_\_ Guardianship: \_\_\_\_\_  
Special Trust: \_\_\_\_\_  
Living Will: \_\_\_\_\_ Health Care Representative \_\_\_\_\_  
Future legal goal: \_\_\_\_\_

**Finances:** \_\_\_\_\_  
Source: \_\_\_\_\_  
Anticipate insurance change: \_\_\_\_\_  
Future financial goal: \_\_\_\_\_

**Safety concerns:** telephone, bathing, dressing, toileting, transfer, feeding, smoke alarm, driving, transportation, emergency exit plan, supervisory need, wandering risk, falls risk  
 None  As noted  Deferred

**Screening:** Other: \_\_\_\_\_  
STD screen: \_\_\_\_\_ Pelvic/testicular exam: \_\_\_\_\_  
Diet: Type: \_\_\_\_\_ Supplements: \_\_\_\_\_

**Habits:** Alcohol: \_\_\_\_\_ Tobacco: \_\_\_\_\_  
Self-resolution re: alcohol: \_\_\_\_\_ Self-resolutions re: tobacco: \_\_\_\_\_  
Street drugs: \_\_\_\_\_  
Self-resolution re: street drugs: \_\_\_\_\_

Sleep: \_\_\_\_\_  
Physical activity: \_\_\_\_\_ Frequency of activity: \_\_\_\_\_  
Sexual expression: \_\_\_\_\_  
Contraceptive need: \_\_\_\_\_

Future childrearing education needs/goals: \_\_\_\_\_

Recent significant stressors: \_\_\_\_\_

**Physical Exam:**

General Appearance: \_\_\_\_\_

Vital Signs: Ht: \_\_\_\_\_ Wt: \_\_\_\_\_ BMI: \_\_\_\_\_

Temp: \_\_\_\_\_ BP: \_\_\_\_\_ HR: \_\_\_\_\_ RR: \_\_\_\_\_ Current pain: \_\_\_\_\_

Skin: no rashes, lesions or ulcers, no swelling, induration or tenderness

Normal  As noted  Deferred

Eyes: normal sclera, conjunctiva, symmetric movement, PERRL

Normal  As noted  Deferred

ENT: no masses, lesions, tenderness or discharge, canals and TM clear, nasal mucosa normal, mouth and pharynx without lesions

Normal  As noted  Deferred

Neck: supple, full ROM, no masses or lymphadenopathy, normal thyroid

Normal  As noted  Deferred

Respiratory: chest configuration normal and symmetric, breathing easy without use of accessory muscles, breath sounds clear to auscultation and percussion

Normal  As noted  Deferred

Breasts: no masses, tenderness, discharge, lymphadenopathy

Normal  As noted  Deferred

Cardiovascular: palpable nondisplaced PMI, RRR with normal S1 and S2 without murmur or gallop, symmetric palpable distal pulses, no edema or varicosities

Normal  As noted  Deferred

Abdomen: normal bowel sounds, soft, nontender, nondistended, liver and spleen size without abnormality, no lymphadenopathy or hernia palpable

Normal  As noted  Deferred

Musculoskeletal: normal spinal curve without tenderness, tone and strength symmetric and appropriate, full ROM of spine, RUE, LUE, RLE, LLE

Normal  As noted  Deferred

Gait: normal speed, coordination and stride

Normal  As noted  Deferred

GU: no masses, lesions, or discharge

Tanner stage:

Normal       As noted       Deferred

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Neurologic: Cranial nerves II-XII intact, symmetric DTR biceps, patellar, ankle, sensation intact to light touch, pinprick, balance steady, movements smooth and appropriate

Normal       As noted       Deferred

---

Mental Status: alert, oriented X 3, recent and remote memory intact, normal range of affect

Normal       As noted       Deferred

---

**Procedures:**

Oximetry: \_\_\_\_\_       Peak flow: \_\_\_\_\_

Vision screen: \_\_\_\_\_       Hearing screen: \_\_\_\_\_

Urine testing: \_\_\_\_\_       Blood testing: \_\_\_\_\_

Other \_\_\_\_\_

Immunizations \_\_\_\_\_

**Initial Treatment Plan:**

1) \_\_\_\_\_

2) \_\_\_\_\_

3) \_\_\_\_\_

Parking validation: \_\_\_\_\_

**Team Conference**

*Health:* \_\_\_\_\_

*Education/Employment:* \_\_\_\_\_

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*Independent living/ Caregiver issues:* \_\_\_\_\_

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*Recreation/ Socialization:* \_\_\_\_\_

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**Anticipatory Care Needs:**

Other: \_\_\_\_\_

Fall risk: \_\_\_\_\_

Seizure risk: \_\_\_\_\_

Choking risk: \_\_\_\_\_

Supervision needs: \_\_\_\_\_

Wandering risk: \_\_\_\_\_

Constipation risk: \_\_\_\_\_

Care for implanted device: \_\_\_\_\_

Trach Stoma \_\_\_\_\_ VP shunt Baclofen pump Pacemaker Vagal nerve stimulator

Emergency exit plan: \_\_\_\_\_

Behavior management plan: \_\_\_\_\_

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**Center for Youth and Adults with Conditions of Childhood (CYACC)**  
**Goal Setting Questionnaire**

The CYACC team would like to get to know you. Complete this questionnaire as best you can. It is meant to help you think about your future needs and goals as you grow towards a satisfying life once you are an adult. There are a number of resources that can help you get there. We hope to work together with you to find the best means to reach your goals.

**Communication:**

Please indicate your communication skills:  speak without help  read without help  write without help  
 use assistive equipment  use a support person

Please indicate which of the following means of communication you prefer:  phone  fax  email  mail

Do you need information or training in the use of a communication system?  Yes  No

**Activities of Daily Living:**

Are you limited in your activities by your health condition?  Always  Usually  Sometimes  Never

In the future, what level of independence would you like to have?  Always  Usually  Sometimes

Never

Are you independent in self-care?  Yes  No

What self-care skills are you able to do? \_\_\_\_\_

What self-care skills are you working on? \_\_\_\_\_

What are your responsibilities in your home? \_\_\_\_\_

What new skills are you working on? \_\_\_\_\_

Which other home skills would you like to learn to do?  
\_\_\_\_\_

Do you use any of the following to help you with activities?

Occupational/Physical Therapy  Assistive Technology/equipment

Assisted living  Personal care attendant  Public health/home health nurse

Do you need assistive equipment?  Yes  No

**Transportation:**

Which of the following do you use to get around? (Check all that apply)

Public transportation  Special transportation services for the disabled  Drive yourself

Personal driver/family member/roommate/neighbor  Bicycle  Wheelchair  Walk

Do you have a driver's license?  Yes  No

If not, would you be interested in working on getting a driver's license with special training and equipment?

Yes  No  N/A

Do you need information or assistance in learning to use a local transportation system?  Yes  No

**Financial Management:**

Are you having problems paying your current expenses?  Yes  No

What insurance resources do you have:  Medicare  Medicaid  Waiver  COBRA

Parents  Own private  Other \_\_\_\_\_

How do you financially support yourself? (Check all that apply)  Employment  SSDI  Trust fund

Educational loan  Other financial aid programs  Family  Personal savings/investments

Would you like more information on any of the above resources?  Yes  No

Which of the following can you do on your own?

Use a budget  Comparison shopping  Pay bills  Use checking and savings accounts

Use credit card when you need help, who helps you? \_\_\_\_\_

Would you like information on programs to help learn these skills?  Yes  No

**Legal Issues:**

Do you have a power of attorney, legal guardian or estate plan made through the court?  Yes  No

Do you have a backup plan for when your guardian may not be able to help you?  Yes  No  N/A

Do you have an advance care plan for your health?  Yes  No

Do you have a health care representative who participates with you in health decisions?  Yes  No

Would you like information regarding these types of legal matters?  Yes  No

**Living Arrangements:**

With whom do you now live?  Family  Friends  Partner/spouse  Alone  Supported living

Where do you want to live in the future?  Stay where I am  Move to Apartment  or House  or Dorm

With whom do you want to live?  Family  Friends  Partner/spouse  Alone  Supported living

Would you like information on assisted or supported living in your area?  Yes  No

Do you receive adequate emotional support from your family?  Yes  No

**Recreation and Leisure:**

What are your hobbies and interests? \_\_\_\_\_

What do you like to do to stay fit? \_\_\_\_\_

Are you involved in any activities in the community? \_\_\_\_\_

Would you like information on any community programs (clubs, activities, sports, etc.?)  Yes  No

Do you have environmental or physical barriers interfering with your participation in activities?  Yes  No

**Education:**

Are you currently in school (i.e. home school, homebound or other)  Yes  No

What school do you attend? \_\_\_\_\_

How much time do you spend in the Resource room? \_\_\_\_\_ General Edu. room? \_\_\_\_\_

What are your grades? \_\_\_\_\_

Do you feel that your school is a safe place?  Yes  No

Have you ever been in a fight at school?  Yes  No

Have you ever been suspended or expelled from school?  Yes  No

What high school did you attend? \_\_\_\_\_ Did you finish?  Yes  No

If you have finished school, which do you have?  Diploma  Certificate of Completion  GED

Are you currently enrolled in college/technical school/ vocational program?  Yes  No

Would you like information on education or employment resources?  Yes  No  N/A

**Employment:**

Are you currently employed?  Yes  No How many hours do you work per week? \_\_\_\_\_

Who is your employer? \_\_\_\_\_ Work Number? \_\_\_\_\_

What are your career goals? \_\_\_\_\_

If you don't have a career plan, what activities are you good at? \_\_\_\_\_

Are you currently working with vocation rehabilitation services?  Yes  No

**Health Habits:**

Have you had a recent loss or gain of weight?  Yes  No How much? \_\_\_\_\_

How many meals do you eat, per day? \_\_\_\_\_

What types of beverages do you drink and how much? \_\_\_\_\_

How many snacks do you eat a day, and what kind? \_\_\_\_\_

Estimate how many servings you have each day ...of dairy products \_\_\_\_\_, other protein \_\_\_\_\_

Fruits \_\_\_\_\_, vegetables \_\_\_\_\_, grains \_\_\_\_\_.

Do you exercise?  Yes  No If yes, how often \_\_\_\_\_ and how long \_\_\_\_\_?

Do you drink caffeinated beverages?  None  1-2 per day  3 or more per day

Are you often worried, anxious or sad?  Yes  No

Does your mood interfere with your daily activities or interactions?  Yes  No

Do you sleep well?  Yes  No How many hours a night do you sleep? \_\_\_\_\_

Would you like information about healthy eating, exercise, or counseling services?  Yes  No

Have you thought about keeping or changing your doctor?  Yes  No

Can we help you find a new doctor?  Yes  No

**PATIENT SPECIFIC QUESTIONS:**

Do you drink alcoholic beverages?  None  1-2 per day  3 or more per day  Occasionally

Do you use any form of tobacco?  None  Cigarettes  Chewing tobacco  Cigars/Pipes

Are you exposed to second hand smoke?  Yes  No

How do you feel about smoking and tobacco use? \_\_\_\_\_

Have you ever misused any prescription meds or used street drugs?  Yes  No Which one? \_\_\_\_\_

Marijuana?  Yes  No Cocaine?  Yes  No Others?  Yes  No

Would you like information about programs to stop smoking, alcohol, or drugs?  Yes  No

**Relationships:**

Who are the people in your circle of friends? \_\_\_\_\_

Where do you get your sources of support? (Circle all that apply.)  School  Home  Work  
 Church  Community  Other

Do you get enough emotional support from your significant other and circle of friends?  Yes  No

How do you get along with your parents? brothers and sisters?

**Sexuality:**

Have you ever, or, are you currently dating?  Yes  No

Male  Female  Both

Have you ever, or, are you currently involved with a sexual partner?  Yes  No

Have you ever been taught to use condoms or other kinds of contraception?  Yes  No

If yes, do you use contraception?  Sometimes  Always What kind? \_\_\_\_\_

Have you been screened for sexual infections?  Yes  No

Do you have questions about how your condition affects sexual expression or having children?  Yes  No

Have you ever had a PAP smear?  Yes  No Last one? \_\_\_\_\_

Have you ever been taught to do a self-exam?  Yes  No

If yes, do you do self-exams and how often? \_\_\_\_\_

Is there anyone who is trying to harm you or get you to do something against your wishes?  Yes  No

Have you ever been a victim of abuse?  Yes  No

Would you like information about sexual development, intimate relationships, preventing sexual infections,  
domestic violence, pregnancy, or genetic counseling?  Yes  No

**Immunizations:**

<b>Immunization</b>	<b>Information</b>	<b>Needed (Yes or No)</b>	<b>Date Completed</b>
<b>Hepatitis B (Hep B)</b>	Patient needs a series of three doses (Hep B x3).		
<b>Measles, Mumps, Rubella (MMR)</b>	Need two doses (MMR x2).		
<b>Tetanus, diphtheria, pertussis (whooping cough)(Tdap, Td)</b>	A Tdap booster is needed after the 11 <sup>th</sup> birthday (if it has been more five years or more since the last dose).		
<b>Polio</b>	Check if preschool series has been completed.		
<b>Varicella (Var) ("chickenpox shot")</b>	Check to see if the patient has had chickenpox. If not, patient needs 2 doses.		
<b>Hepatitis A (Hep A)</b>	Two dose series that may be indicated for those who travel outside of the U.S., use illegal drugs, have a clotting factor disorder, chronic liver disease, or a male who has sex with another male.		
<b>Influenza</b>	Recommended each year for anyone who has a chronic health problem (i.e. asthma, diabetes, etc.)		
<b>Pneumococcal disease ("pneumococcal shot")</b>	May be given every ten years for all patients with cardiovascular, respiratory, or immune system related disease.		
<b>Meningococcal disease</b>	All 11-12 year olds, teens about to enter high school, and older teens who plan to live in a college dormitory.		

Adapted From: Blomquist, KB. *Orthopaedic Nursing*, 17 (3), 27-35, 1998.

**Healthy & Ready to Work MODELS Project**  
*Interview with Ronna Linroth*  
**Gillette Lifetime Specialty Healthcare - Minnesota**  
*Interview conducted on November 26, 2007 and January 14, 2008*

**Ronna Linroth** – Manager of adult outpatient services. Operations manager for clinic itself. Manages day to day, client satisfaction, etc.

- flat organization “somewhat unique”
- CEO, medical director, and VP have open door policy
- matrix management for outpatient clinic

Gillette Children’s Specialty Healthcare (trademark) = umbrella  
Gillette Lifetime Specialty Healthcare = clinic itself (transition clinic)

There are separate managers for each of the services offered by the clinic i.e. manager for rehab, social services, psychology, child and family services. Number of managers depends on amount of services. Ronna has six or seven.

### **Gillette Lifetime Specialty Healthcare**

Wanted to grow beyond cerebral palsy. One year pilot was adults with cerebral palsy – conducted in August 2001, saw first patients in October. Ran for 14 months, then had permission to expand beyond CP. Added spina bifida, neurology, and others. Under original vision, idea was that pilot would move to other outpatient service arena, w/adult component in each. Needed to be able to programmatically grow - evidence based.

**Gillette all designed around pediatric population (waiting rooms ped size, ped graphics, etc.)**

Environment to reflect patients they serve – changed environment to be attractive to adults. Trademarked particular concept “age appropriate care” – adult services for people w/disabilities.

Original vision would cover all adult services across sites, Gillette designed to serve adults = 16 and older

**First phase** = Create adult model of care. Determine their philosophy, services, etc.

**Second phase** = bridge models – move from pediatric to adult model. Created four different pathways. (listed below)

Don’t want to fragment care. Specialty clinics are in the same place, same building, but with different offerings depending on providers avail.

#### **Pathways to care**

- 1) An individual can call and make an appointment for the lifetime clinic. They can decide to attend transition clinic at hospital. (Call and schedule directly)

- 2) Jennifer Wilhalmy – adult NP who can help match personalities with providers based on need and availability. Part of her role is to generate “summary note” – describing what current problems to be attended to are, providers/services available.

Originally were not seeing children who were ready to move into adult model. Age of transition was left in providers hands to determine with families \*\*\*still the case. Have undertaken more education endeavors to help families understand difference between pediatric and adult model.

- 3) Invite pediatricians w/large adult populations to provide adult model to patients in the lifetime clinic.
  - used to be in NEW BRIGHTON – Suburb – they are now less than a mile away from hospital, in St. Paul. Because of geography providers didn’t come. Good news = good environment, provide services in adult model of care. Just didn’t work logistically.
- 4) For “recalcitrant ones” – Some adults who just don’t like change, afraid to change healthcare providers. In order to demonstrate connectedness of services, talking to one another etc, providers would conduct co-visits. For example at next scheduled appt., Ronna would go to ped clinic, and present to individual what the clinic was, the model of care, answer questions, etc. and then physician recommends individual go to adult care. Good to show adult and pediatric providers talk to one another. Pediatrician says I won’t see you, here is an adult provider. \*\*literature to back it up. Often times patients don’t have confidence that provider understands disability, so it’s good for adult providers to meet with pediatric Providers. Face to face. Some people need to see the provider relationships.

**Third phase** = Currently in phase 3. What else needs to be done for transition?  
Transition verses transfer of care. In retrospect, our experience is not necessarily unique.

Phase one was designed as an adult model. The first phase – adult model, but mechanics of what happens, receive most difficult patients. (Chronic, noncompliant, substance abusers, etc)

Have between 1000 and 1200 that should be at Lifetime Specialty Clinic (but are currently at Gillette)

2008 projection: will have 47000 outpatient visits for all of Gillette.

2006: had 18-20% of potential eligibles moved to adult services.

\*\* shows pediatrics is still being burdened

If people were seen by Gillette as children, then come back 20 years, don't necessarily consider themselves new to organization. People also self identify. Ronna there six years – Gillette has doubled in size.

Dr. Gillette – went to state legislature (Gillette health now 110 years old) stressing how important care of children with disabilities is, less expensive, etc. wanted to have a children's state hospital. Mid 1970's, went to private non-profit.

In pilot phase, looked at all providers in metro community – visited target sites to determine who was served, and who wasn't. Gillette wanted to fill the gaps not duplicate services.

Refer back and forth, work with coalitions to see funding. Bring a sense of public awareness and advocacy.

- Partner - "Courage Center" – deals with spinal chord injury.
- Abbott W. Western
- Fairview

Hours of operation: Monday – Friday, 8:00-5:30

## **I. Physical/Organizational structure**

Considered a hospital based clinic – but an offsite from main hospital. In St. Paul, one mile away from hospital.

Urban location

**Collaboration:** Refer back and forth, work with coalitions to see funding. Bring a sense of public awareness and advocacy.

Wanted to make sure not duplicating community services already working. In that sense, have been very collaborative. Refer back and forth. Work together through coalitions to move legislatively, increase funding, public awareness, collaborative environ in world of adults w/disabilities. Refer for spinal cord injury, multiple sclerosis, etc.

- Partner with
- "Courage Center" – deals with spinal chord injury.
  - Abbott W. Western
  - Fairview

Gillette Lifetime facility is fully accessible – extra wide hallways, multiple surfaces, power lifts, in ceiling lifts, all designed around adults with disabilities. Also flexible when can make appointments.

Don't provide billable services by email – email is not secure.

Interpreters: Spanish interpreter on site, and contract w/other interpreters in town.

**Other Comments:** Gillette Lifetime Specialty as adult model of care in a pediatric hospital

## **II. Staffing**

Have specific transition staff – Ronna (full time) hired specifically to create this program. First of dedicated staff. Has written transition policy.

### **Comments:**

Has put together policy statement and ACTION plan – Ronna met w/Gillette staff and came up with plan. Have a social worker dedicated to work with families in transition. (Transition planning starts at age 14) want to be talking about transition so have written transition plan by the time ready to transition. Have one at 16 years - physician dictation (idea of transition plan) available electronically to everyone in office. Social worker talks w/family and provider.

Also developed system level position – what were the systems in place to make transition possible – i.e. Communications, publications, i.e. go to age control language.

### **ON SITE**

Nursing supervisor, 4 RN, 2 nursing assist

2 social workers, one at .8 other at .6, also sees patients at hospital, psychologist at .5, medical director (hired specifically for adult services at Gillette) - bridges adult and outpatient

Certified NP

7 therapists

14 – IT staff (feeding, prosthetics etc)

Mobile outreach

Current patient load – Just physician visits for lifetime only, projecting 3500 - 4000 patients for 2008. For first three quarters in 2007, have seen 4078 visits in clinic – physician appointment related.

Patient care team appt that precedes physician appointment. Full team comes when new to clinic. 1 hour long appt. if returning, have 30 min patient care team appt. Everyone weighed. If needs aren't being met, see if they want to see their therapist. .

Adults with disabilities as advisors to program. People want to be looked at as WHOLE people. Nursing assessment as all physician review.

Specialty Providers: Not all onsite everyday, but can make referral. If they don't offer service, can refer to someone else.

Significant advances in attempts to articulate what transition means, and developed tools to explain. Published things on transition.

- Newsletter "pediatric perspective" – goes out to regional provides – primary care.

Publications on Gillette site...

- Assisting in the transition to adult focused healthcare-newsletter. Go to archived – vol. 16 #2 2007
- "Never too early to talk about adult hood"
- "Making the transition" – resource flyer

Transition resources - flyers w/services at Gillette, patient education fact sheets.

TOOLS FOR TRANSITION: "Make Your Move" (3 ring binder) \*\*\*

\*\*\*this transition tool as suggestion for other programs – written for a sixth grade level (for clients and caretakers)

Gillette has chartered committee on transition – anywhere between 12 and 20 people.

Now in process of second tool "As the Journey Continues" transition guide for parents and care givers – starts w/ article on cyclical grief. Acknowledge grief as carved into different group, but want to move past that. Acknowledge sexuality. – written for parents and caregivers.

Talk about travel and recreational information. So people's lives won't be limited. Aging parents caring for aging children.

### **III. Medical Home**

School/work accommodations: Starts w/meeting w/psychologist, includes independent living evaluation, functional performance components. Computer access assessment to look at how individual w/disability can access all that a computer can do—switches, tools, software, etc.

IEPs: Working with vocational rehabilitation for work and preparation to work. Not fully developed program at this point.

**Comment:** Started parent –peer match program. Several summer camps recreational and skill building. Transition social worker works with families and child.

Other comment: There is a lack of understanding around concept of transition - what it entails. If people haven't read about transition, it's seen as "transferring care" – same

care, different place. Want to focus on skill building, partnership, more than single event. Never goes as fast or smooth as one would like. Complex patients, two different cultures (pediatric and adult).

Based on social justice model verses social welfare. Need to educate for democracy. People need to know choices, and have a right to refuse treatment, prioritize, etc. social justice incorporates citizen model – equal and democratic partners. Society views the issue as an acute health care problem that deals with problems as they arise. Very little covered around adults with disabilities.

Ronna's Concepts: intentional, planned, skill building, as a process – more than a single event.

#### **IV. Financing/Insurance**

Take all payers. Will find way to pay for services. Charitable care pool within Gillette.

No MCHB or Title V funding.

#### **Recommendations:**

Shriners – Montreal

Sue Maherky – Chicago. Spina bifida work. Patient education.

John Reiss, Bob Gibson – transition listserv a  
Cleveland

#### **Final Thoughts**

**Useful operational Tools** – Chartered committee on transition.

In next phase – want consistency in physician dictation. Will be modeled after medical home care planning.

Self referral for transition resources – information requested, meet w/transition social worker, have social worker call patient, etc.

Cost-benefit analysis of transition

#### **Follow up 1/14/2008**

#### **Newsletters**

Newsletter for patients and families – quarterly newsletter

Pediatric perspective – audience is referral sources, primary care providers, family practices, etc. In part a marketing vehicle, but also to provide education and information re: when you need a specialist

What phase are you in at the moment? – Phase 3

How to help youth of various capabilities acquire the level of skill in order to be good advocates for themselves, make decisions about their healthcare

What families can do:

Help youth speak for themselves, call and make appointment themselves etc.

Am I competent, in what areas do I need help, what legal processes, how will insurance/benefit change, how will I navigate/identify gaps

Binder: basic binder circulated to patients and families

More advanced “the journey continues”

Putting together curriculum for providers inside and outside Gillette

No link to Title V

Worked with MN department of public health – SHCN grant

Gillette has contract to provide outreach services

### **Evaluation**

Started to put together a formal evaluation of program –

For first three years, designed patient satisfaction survey, based on feedback from adults with cerebral palsy, based on adult advisory committee, see if applicable to new populations

Items identified as dissatisfied – why chose pediatric versus adult environment, knowledgeable about disability

Organization signed contract w/outside agency for satisfaction survey – all of Gillette children’s specialty health care getting evaluated, ped and adult form

Given to patients at beg of visit, then return at end.

Also mail out after visit – 17% response rate

Also have staff retreat, usually first Friday of December, meet for half a day, all staff present, talk about program development, service recovery – realize this is where they’ve failed, have had to act differently

Is the word of mouth within community pos or neg? are people coming over and staying, or do they want to go back to pediatric model?

Very high number of people stay

Where would people go back to? Ped providers would take them back.

Do we have the right service menu, or do we need to recommend out – all talked about at December meeting. About forty people attend. Program development staff.

Lifetime – increased patient visits 35% 2006-2007

What percent of those transition within a year – strong word of mouth in community

## **Policy**

By age 16, providers should be talking to patient and have a plan

By the time someone is 18 – advise don't make change in primary and specialty care simultaneously –

\*\* too much change at once is not good, too much change is bad – change one and then the other

Outcome data – no, have fluid data

We have every year been underwritten by Gillette foundation, raises funds, we are fee for service, keep looking at staffing model

Arthritis – have good system for those who have grown into adulthood, already is a clinic, good providers who address rheumatoid arthritis, so don't offer those

## **Collaboration**

\*\* too many gaps to fill to waste time duplicating services

\*\* consider themselves good neighbors, don't duplicate services

Do collaborative conferences, but don't take work away from them, compliment one another

\*\* environmental scan\*\* -- see who's out there, who they are serving, how satisfied are they with their services

Honest relationship to others in community

How would an organization pay for such a thing

Look at who you are serving – can you design adult services to meet their needs?

Adults w/polio-indemnity insurance

MDA – muscular dystrophy association – if you are recognized as one of their clinics, meet their standards, then some financial services available to patients

Cystic fibrosis as well

Look at fiscal balance

\*\* work with disability groups to help you raise funds

\*\* partner with organizations to help you

Depends on the community – what the culture is of the place

Who has relationships, who can get things done

Expressing experiences, don't know how would be different if different players

If I didn't have good operationalization skills, relationships would be great but wouldn't get things done.

\*\*Need someone who can operationalize a concept. \*\* be tenacious

Were an organization that had a vision before RL was hired  
Social welfare model

RL – manager of adult outpatient services, day to day operations manager for clinic,  
scope is across adult services for Gillette

Facilities manager for building

Operations manager – making sure everyone working well together on site and patients  
needs are met

Pulling together rehab, social services, etc

Organizational structure of matrix management

Gillette has a lobbyist – takes on financial issues – don't lobby, work with the groups  
Consortium of citizens with disabilities

Commissioned committee to report back to

Safe patient handling committee

**Helpful Links**

<http://www.gillettechildrens.org/default.cfm?PID=1.3.8>

**Healthy & Ready to Work MODELS Project**  
*Interview with Nebraska program*  
*Interview conducted on January 23, 2008*  
**NEBRASKA – Shirley Dean**  
Transition Consultation  
Portals Project – referred by state

**Background**

Monroe Myer Institute on University of Nebraska Medical Center Campus  
Monroe center for genetics and rehabilitation  
Train folks in those disciplines

Nebraska Center for Disabilities Monroe Myer Institute for Genetics and Rehab  
Not a physical center, just key staff who work on rehabilitation  
Within Monroe Myer Institute at U of Neb  
This is where youth come for consultation

Nebraska Dept HHS applied for Centers for Medicare and Medicaid Services grant in  
October 2004  
Received grant, contracted with Monroe Myer Institute to carry out aspects of grant. We  
have transition consultation and several other projects related to it.

Also lend grant

Set up on a demonstration basis 2004 – 2008  
Transition project started September 2005 with \$\$ from Nebraska HHS, had seen some  
youth before that. Consultation service running from that. Now on no cost extension from  
that grant. In operation until October 1<sup>st</sup>, then HHS will find a way to make this service a  
service of the A and D waiver (age and disabled Medicaid waiver)

Waiver available to every state, depends on how you write your waivers

Over three years later on no cost extension, HHS working to convert this service  
(transition project) into A&D waiver, in order to purchase this service through A&D  
waiver. (pays for services for families up to a certain cap)

A decision to be made between HHS and whoever at federal level (at CMS) decides.

Sitting on pins and needles and hopeful that they will get \$\$.

**Clinic that offers consultation services**

Serving youth ages 15-21. At first were trying to target 15-19 year olds. Accept people up  
to 21 if still struggling with transition issues.

Youth with disabilities and complex medical conditions and who are receiving A&D  
services, medically handicapped children's program, eligible for SSI.

### **Referrals**

Most referrals come through HHS coordinators, through A&D program or medically handicapped children's program.

Referrals not typically coming from physician. Focus on services coordinators making referrals because grant written as A&D service.

### **HHS Coordinators**

Every youth on A&D waiver and medically handicapped children's program have a Service Coordinator. Their job is to help the family and youth, support them, get services, help youth remain at home rather than move into long term care facility. Don't know about their training, but part of our program is to provide education to the coordinators re: transition.

Workshops that they can come to – video conferences, we mention transition consultation and the need for them to talk to families about it. They talk to families about it on their regular visits, the coordinator, family and youth, can call Shirley about the service.

### **Teleconferences**

Teleconferences are educational series for coordinators to learn about the issues, part of our transition project. Held every other month.

Hundreds of service coordinators. Different info presented at every one – could be on genetics, cystic fibrosis, transition, etc.

HHS coordinators give us the topics – Project Officers. “Do a training on this topic” – we recruit, find the expert, and do the training.

\*\*video conferences – primary way that we disseminate info re: our services

Trainings can be on any topic, then maybe a sentence reminder of transition program.

We don't develop the conferences ourselves, we draw on experts from Monroe and other agencies.

Hundreds of Transition coordinators refer youth based on what they hear from video conferences through their employment from HHS.

Typically a service coordinator will call transition program and will ask questions. Families fill out questionnaire that the service coordinators have, coordinator sends it to me, along with medical records, IEPs for the family, etc. If they don't have them, we can ask the family for the records.

## **Process**

I am the first contact for service coordinators.

- 1) Have a nurse, she and I review records, see if we need more records, updated IEP, etc.
- 2) almost always makes sense for us to then set up appointment.
- 3) Then I'm in charge of the scheduling for the consultations – happen once a month. I talk to families and find out when they will come in. If they are confused, don't feel they need to come in, sometimes they don't come in.

They call and we schedule an appointment.

**Our physical space:** Wheelchair accessible, tables that go up and down, special needs friendly.

Services coordinator is in the loop, knows when appt is. Shirley sends letter to family explaining program, when they should come in. Also send one to service coordinator. Records are sent out to team who will see family.

**Transition clinic held once a month for half a day.**

**Were seeing one youth, now seeing two.**

## **Transition Teams**

Nurse – full time staff, works with a lot of different clinics

Shirley – Part time on this project

Dr. Brad Schafer – directs project

Meet the third Friday of the month. Team available in the morning.

WE are not in a great demand.

HHS – have 200 youth between 15-19 on A&D waiver program.

Don't know how many with medically handicapped youth.

## **Intake**

2 youth in four hour period for consultation

Upon arrival, youth checks in at patient check in desk.

We have someone meet them there because building is a maze.

See the nurse first. Does height, weight, vitals, etc. She gives them a list of team members they will see that morning. Each of the people on our team goes in one at a time; we each go in and talk with them. See a psychiatrist who specializes in adults working with disabilities. See developmental pediatrician specializes in working with children with disabilities. See med. Peds. Doctor. Myself, and another staff, look at non-medical issues. Six people total, have all looked at documentation before youth/family arrives, but we have not talked to each other. We can observe when psych talks to the family (with their permission) so not overlap question. But not all six observing for all sessions. Typically have social work student as well.

**Goal of visit**

Assessment of youth and where they are in terms of reaching their goals. Looking at current diagnosis, re-evaluate diagnosis, medications re-evaluate, etc.

No overall tool, each does own assessment. But everyone has their own tool.

Youth fills out Healthcare Assessment tool they fill out before they come in – looks at how they manage their own healthcare i.e. do they take their meds on their own, do they know how to make an appointment, articulate condition etc.

They identify on their tool and questionnaire what they want to talk to the team about.

Team zeros in on those things, as well as routine questions.

Might ask for specific healthcare providers, transition to adult care, etc and we put together recommendations.

**When they leave**

During the two hours, have had a chance to talk to professionals about med issues, services issues, etc. Hopefully have gotten their questions answered.

Following discussion with the team, the family receives a resource book – made individually for them. Includes transition planning and info about services that apply to them.

**Telehealth**

See youth for all over the state. Some via telehealth. Can see youth that would have had to drive 8 hours, instead chose telehealth. Every hospital and some Health depts. Has telehealth hook up, so relatively close.

While I meet on non medical issues, medical team puts together list of things for youth to do. Nurse comes in to family to describe verbal recs. Family receives written report, can choose who else would like it be sent to i.e. doctor.

Don't have a template, will send outline. (and possibly resource book, health assessment, etc)

Seen 26-28 youth in past three years

Always include a recommendation to return

Project has two visits ...

If family has questions between visits, can call in between (visits spaced out six months or a year apart)

Can refer to Easter Seals Benefit Analysis – questions on work benefits, work, etc. Work with families to understand benefits, discount expenses because of disability, etc. Don't provide directly from transition clinic, refer to them based on meeting.

During time in between visits, we might be talking with them. Service coordinator might be talking with them. We and SC can help family get hooked up with services.

We have a lot of info about resources, we can research something youth might need.

We update the transition plan, check in with them about how the plan is going. Down the road, I might email the mom re: information. Contact varies during the six month period, but at some point we update the plan, if we haven't called them and they haven't called them.

### **Return visit**

Ask them who they want to see during second visit. Always see at least one medical visit (nurse always comes) always see me and navigator to help them find services. When we update the plan, see where they are in carrying out recs and what questions/concerns

Meet with them in person to see how plan is going if there's need for f/u. Every month? Every three months? Six months? Etc

Physician only in contact via medical records.

If there are questions for change in prescription, etc, up to family or service coordinator to follow up with regular psych. Or provider. Can also send written report to children's psych.

### **Evaluation**

Don't have any evaluation

Faculty that teach residents and med students--see how info they learn here might be applied to teaching students. They train 80-90% docs in Nebraska. Also have access to teleconferences.

Physicians training Curriculum and Resources for transition CYSHN

We aren't overseeing how it's taught at medical school. We have talked with med faculty re: how they thought materials could be used. Schafer (ped genetics training) has talked to residents and med students, how this could be in Electronic record system, etc.

### **Barriers**

Distances – address through telemedicine

Another component at HHS level – young adult advisory council made up of CYSHN.

Have had parents and prof review our materials and give us advice. Not formal advisory committee.

Youth advisory meets every other month. Initially someone did attend, but now phased down hours. We are in the loop because we get the minutes.

Shirley will send us materials via email.

Program sum eval

Healthcare assess

Resource book for youth/family – catered to ind. Family. i.e. if going to college, etc. can tell them about ARC, etc.

Template of report from first visit

Outline of written plan

Notebook/physicians

# **Portals Medical Transition Project: Program Evaluation Summary**



**Munroe-Meyer Institute  
University of Nebraska Medical Center  
Omaha, Nebraska**

**October 2005 through September 2007**

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# 1. Introduction

## ◆ Program Background

The Nebraska Department of Health and Human Services (HHS) received a grant from the Centers for Medicare and Medicaid Services (CMS) beginning 10/1/04 to improve the medical transition process for young adults with special health care needs who are preparing to move from pediatric to adult-based health care. It was anticipated that the outcome of this project would be an amendment to the Nebraska Home and Community-Based Aged and Disabled (A & D) Medicaid Waiver to formally include medical transition planning and benefits analysis in preparation for employment. Nebraska was one of only two states selected to pilot the development of this new waiver service that could ultimately serve as a national model.

## Project Activities

Nebraska Health and Human Services contracted with the Munroe-Meyer Institute to complete three components of the Portals Transition Project including development of a health care transition clinic, videoconference series for A & D Waiver Services Coordinators, and an education component for family medicine physicians. The purpose of each of these three components is briefly described below:

*Clinic Model.* A primary component of this project was to design and implement a transition clinic staffed by physicians and specialists from the Munroe-Meyer Institute (MMI). The first clinic was held 9/9/05. An interdisciplinary core team, including a developmental pediatrician, physician in internal medicine-pediatrics, adult psychiatrist, nurse, youth/family advocate, and navigator completes the assessment of the youth during the first visit. A summary report and initial transition plan is provided to the youth and family as an outcome of the assessment process. During the second clinic visit the youth, their family, and team review any additional assessment information completed as recommended from the first visit. The initial transition plan is finalized to support the youth and their family in their transition to adult based health care.

*Physician Training.* The second project component was on physician education with the expectation that training could increase family practice physicians' acceptance of youth with special health care needs into their services. The clinic activities served as a site for family practice physicians to participate in an orientation and observe the clinic. A notebook of Physicians Training Curriculum and Resources on Transition from Pediatric to Adult-Based Health Care for Youth with Special Health Care Needs was provided as part of the orientation, education and discussion. A total of eight physicians participated in this component of the project, beginning 7/06 through 9/07, with the two remaining UNMC Family Medicine Faculty having met with Dr. Schaefer individually.

*Services Coordinator Training.* The project and HHS staff identified the importance of increasing the awareness and skills of the services coordinators regarding the clinic and

health care issues of the youth with special health care needs as they were targeted to serve as one of the primary referral sources for the clinic. This grant sponsored a monthly statewide videoconference educational series led by Dr. Brad Schaefer and presented for Child and Adult Aged & Disabled Medicaid Waiver Services Coordinators. Beginning 5/17/06, the series focused on disseminating information on the clinics and transition issues for children with special health care needs. A total of 15 videoconferences were held beginning 5/06 and continuing through the end of this grant year.

## **2. Evaluation Findings**

### **◆ Evaluation Methodology**

The purpose of the evaluation of the Portals Medical Transition Project was to determine the success of the program in implementing the three components of the project to date and to identify recommendations for improvement of the processes. Three primary questions guided the evaluation process including:

- How successful was the project in supporting youth and their families in the health care transition process?
- How effective was the project in supporting family practitioners in assuming the care of youth with special health care needs into their practices?
- How helpful were the videoconferences in supporting services coordinators' understanding of transition issues for youth?

### **Data Collection Process**

Four primary evaluation strategies were used to assess the effectiveness of the project. These strategies included:

- Documentation of the number of participants in each of the three components of the Portals Medical Transition Project.
- Completion of satisfaction surveys by youth, family members and services coordinators on the effectiveness of the clinic in supporting health care transition.
- Completion of satisfaction surveys by physicians on the effectiveness of the orientation, resource materials, and clinic observations on their ability to serve youth with special health care needs.
- Completion of satisfaction surveys by services coordinators on the helpfulness of the educational videoconferences in understanding issues related to transition.

## ◆ Number of Program Participants

Participants in the program included:

- Nineteen (19) youth and their families who participated in the clinics since the clinics began. These youth were seen between October 2005 and September 2007. Additionally, a staffing was held for one youth with the Transition Team, the Services Coordinator, and HHS staff. (The family had to cancel attendance at the clinic at the last minute.). Resource information was mailed to another six youth and their families, who were unable to participate in clinic. Of these youth, five were in college (four on MHCP and one on A & D Waiver.)
- The youth seen in clinic represented a wide range of medical diagnoses, including autism, seizure disorder, cerebral palsy, mental illness, cognitive disabilities, traumatic brain injury, scoliosis, vision problems, paraplegia due to accident, brain tumor, and spina bifida. They ranged in age from 15 to 21 years. The families were geographically distributed across the state, with nine living in the metropolitan area and the remainder living throughout the northeast, southeast central and western parts of Nebraska. Two of the families were Spanish speaking and required an interpreter and translation of reports and Transition Resource materials.
- Although the majority of the children who are on A & D Waiver do not have significant cognitive impairments, the majority (80%) of the children that were referred from A & D Waiver and were seen in the clinic did have cognitive impairments of which most were severe. For youth on the MHCP, only 27% of the youth who came to clinic had severe cognitive impairments. More of these youth had goals of competitive employment and/or post secondary education.
- 15 videoconferences were broadcast for services coordinators throughout the state.
- Eight physicians shadowed the clinic team and participated in training to date.

Dr. Bradley Schaefer met individually with the 10 faculty of the University of Nebraska Medical Center, Family Practice and Internal Medicine. These physicians agreed to observe one of the Transition Clinics. Eight have observed clinic and participated in the training orientation to enhance their understanding of the health care needs of youth with special health care needs and to better prepare them to serve this population as they become adults. The remaining two physicians were unable to participate, due to scheduling conflicts.

## ◆ Result: Effectiveness of Clinic on Youth's Transition

### Clinic Model

As part of the grant's continuous improvement process, consumers were asked to provide feedback regarding the clinic. Twenty-three (23) consumers (family members and the youth) completed a satisfaction survey, either through a telephone interview or completion of paper/pencil survey. It was prioritized to obtain youth feedback whenever possible.

*"There was enough time to get all of my questions answered. The group was caring, was able to get to the point. Overall, it was wonderful.".....a parent*

Overall, the consumers rated the clinic positively (3.43) (based on a 4-point Likert scale with 1=strongly disagree and 4=strongly agree). They agreed the clinic addressed their concerns (3.83). The consumers reported their ideas were valued (3.56) and that they were part of the decision making process (3.32), suggesting implementation of family-centered principles.

One parent recommended that the team needs to interpret the medical information in a more understandable way. Another recommended the report be sent to their physician sooner, so recommendations could be implemented quicker. They noted that the handouts and materials were a valuable resource.

*"I liked the separate evaluations and I shared one of the resources with my teachers.".....a youth*

## Results Based the Youth's and Family's Response

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Rated
1. My concerns were addressed by the clinic team.	1	2	3 43% (10)	4 57% (13)	
2. The information provided was clear and understandable.	1	2 9% (2)	3 48% (11)	4 43% (10)	
3. My ideas were valued by the team members.	1	2	3 48% (11)	4 52% (12)	
4. I liked the way the assessments were structured.	1	2	3 65% (15)	4 35% (8)	
5. The resource materials provided were helpful.	1	2	3 43% (10)	4 57% (13)	
6. I felt part of the decision-making process.	1	2 9% (2)	3 56% (13)	4 35% (8)	
7. The clinic team provided me with information about community resources that could help meet my needs.	1	2 9% (2)	3 52% (12)	4 39% (9)	
8. The clinic helped me and/or my family get other needed services.	1	2 22% (5)	3 39% (9)	4 39% (9)	
9. Overall I found this clinic to be very helpful.	1	2	3 60% (14)	4 40% (9)	
10. The information from this clinic will help me as I (my youth) transition to adult services.	1	2	3 65% (15)	4 35% (8)	

The services coordinators (8) who were involved in the clinic process rated the clinic positively (3.63). They reported that they were impressed with the holistic interdisciplinary approach, the thoroughness of the report and the later follow-up. They noted that handouts and materials were a valuable resource.

### Results Based on Services Coordinators' Responses

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Applicable
1. The clinic team addressed the family's concerns.	1	2	3 17% (1)	4 83% (6)	
2. The information provided was clear and understandable.	1	2	3 17% (1)	4 83% (6)	
3. My ideas were valued as a team member.	1	2	3 57% (4)	4 43% (3)	
4. I liked the way the assessments were structured.	1	2	3 83% (6)	4 17% (1)	
5. The resource materials provided to the family were helpful.	1	2	3 25% (2)	4 75% (6)	
6. I felt part of the decision-making process.	1	2	3 57% (4)	4 43% (3)	
7. The clinic team provided the family with information about community resources that could help meet their needs.	1	2	3 50% (4)	4 50% (4)	
8. The clinic helped the family get other needed services.	1	2	3 63% (5)	4 37% (3)	
9. Overall I found this clinic to be very helpful for the family.	1	2	3 37% (3)	4 63% (5)	
10. The information from this clinic will help the youth transition to adult services.	1	2	3 43% (3)	4 57% (4)	

Initial feedback from seven family practice physicians who participated in the clinic as part of a training effort found the experience to be very positive (3.48) [based on a 4-point Likert scale with 1=strongly disagree and 4=strongly agree]. They had limited experience in their current practice with young adults with disabilities. They felt that as a result of this experience that they were more likely to increase the number of young adults with disabilities that they would follow in their practice (3.29). It was noted the comprehensive list of resources they were given would be very valuable in their practice

*"I liked the Youth Transition Plan. it will be very helpful to me as a provider when I take over the youth's care.".....a physician*

### Results for the Physicians

	Strongly Disagree	Disagree	Agree	Strongly Agree	Not Applicable
1. I found the following experiences to be very helpful in learning about addressing the needs of young adults with childhood on-set disabilities or health problems: <ul style="list-style-type: none"> <li>Observing the clinic.</li> </ul>	1	2	3 29% (2)	4 71% (5)	
	1	2 29% (2)	3 14% (1)	4 57% (4)	
	1	2	3 57% (4)	4 43% (3)	
	1	2	3 29% (2)	4 71% (5)	
2. I felt prepared to care for a young adult with childhood on-set disabilities prior to participating in this transition clinic.	1 4% (1)	2 43% (3)	3 43% (3)	4	
3. I feel prepared to care for a young adult with childhood on-set disabilities after my participation in this transition clinic.	1	2	3 71% (5)	4 29% (2)	
4. I am willing to increase the number of young adults with disabilities that I follow in my practice or to begin serving this population.	1	2	3 40% (2)	4 60% (3)	
5. I am already serving this population of young adults with disabilities in my practice.	1 25% (1)	2 50% (2)	3 25% (1)	4	
6. I plan to use some of the materials and resources in the notebook as part of my training of residents or medical students.	1 20% (1)	2	3 40% (2)	4 40% (2)	

### Focus Group Findings

A focus group was conducted with the majority of the clinic team members in February of 2007. A summary of their input is provided in the following:

**The clinic procedures were reviewed and modified to run more effectively.**

One of the primary purposes of the pilot was to test out a proposed model for an interdisciplinary transition clinic and modify procedures to increase its effectiveness. The team reflected that over the previous year and a half the team has refined the clinic process to increase its effectiveness of addressing the transition needs of the youth. For example, a summary plan was developed to augment the written report for the family and the nurse specialist now meets with the family to summarize the recommendations of the team on the day of the visit. Overall, they felt they have developed into a cohesive team that worked well together and the clinic format provided an opportunity to learn from each other. Although the clinic initially was conceived to primarily address the health issues related to transition, the team has addressed a wide spectrum of issues. The ability to use a holistic approach has helped to address the needs of the family. All team members felt the clinic via tele-health was very successful and recommend continuing to make this approach available for families who live a great distance from the Omaha area.

A parent suggested that families be given a list of the professionals they will see at clinic. This suggestion was implemented. Another parent suggested that we not use as much technical medical language in our report. We re-wrote the report of that youth to make it more family friendly and we have kept this in mind in the reports completed since then.

One of the ongoing issues, especially during the first year, was the limited referrals to the clinic. During that time period, most referrals were from the Medically Handicapped Children's Program. Referrals from the Child A & D Waiver increased during the second year. No referrals have been received from the Adult A & D Waiver, although they provide the Waiver Services for youth beginning at age 18. More marketing is needed for the clinic to meet its capacity.

Clinic staff have found some barriers in accessing needed resources for families. For example, extensive work was done with one youth who is diabetic who needed funding for necessary supplies after she turned age 21. Accessing adult specialists, e.g., orthopedist, who have the expertise to serve persons with special health care needs, continues to be a challenge.

**The clinic benefited the youth and families.** The team identified a number of ways the youth and families benefited from participation in the clinic. The team facilitated a dialog for the family and youth to express their perspectives about transition, the youth's goals for the future, and begin to discuss what steps needed to be taken. The medical evaluations provided useful information about the youth's current medical condition, identifying issues that needed to be addressed (e.g., inappropriate medications, misdiagnoses, behavioral issues). Medications were

reviewed and recommendations were made as needed. Nutrition and exercise were an issue for many youth and for several these areas were being addressed for the first time. In order to address the broad spectrum of issues presented, the team identified appropriate community resources and supported the family in making these referrals. For example, clinic staff helped youth and their family's access community resources such as respite, free dental care and connecting the youth with opportunities for social interactions.

The project staff have continued to increase the number of resource materials that are made available for youth and their families, as well as information about services that may be of interest to them in their area. As needed, project staff research services and added resources based on the goals and needs of the youth and their family.

### **3. Conclusions**

#### **◆ Lessons Learned**

The team felt that a number of lessons were learned during the last two years of implementation. They are listed in the following:

- ◆ Although the primary focus of the clinic was medical, it has been important to have a broader scope and to holistically address all of the youth's needs.
- ◆ The navigator role is helpful in providing follow-up with families regarding the youth's plan that was generated based on the clinic recommendations.
- ◆ It was important to add a debriefing with the youth and family at the end of the clinic to review the recommendations after the team met. This provided the families with the recommendations so they could immediately begin to address the recommendations.
- ◆ Ongoing contact with Services Coordinators to increase their awareness of the transition clinic was determined necessary as a strategy to increase the number of referrals to clinic. Initially referrals were limited. Following the development of informational materials, i.e., a fact sheet and brochure, referrals increased. If the clinic is replicated, it would be recommended that informational materials be developed immediately to facilitate referrals to the clinic.
- ◆ Partnering with Services Coordinators is essential as they help youth and families solve difficult problems they face.
- ◆ The Young Adult Advisory Council was an important advisory group to the project. For example, Young Adult Advisory Council provided input that they felt the clinic should be called something different in order for youth to be more receptive to coming to the clinic. The term "Transition Clinic" was changed to "Transition Consultation". Convening the group on the onset of the project would have been beneficial.
- ◆ The involvement of UNMC Faculty in this project was extremely positive and the ways in which they were involved seemed to be very effective based on their feedback, both verbally and on the Satisfaction Surveys. Various faculty

members mentioned to us different ways they plan to utilize the Physicians Notebook materials in their roles of training medical students and interns, e.g., one physician mentioned he planned to write a case scenario that included a person with a disability to be used in training; another mentioned that she is going to be in charge of the curriculum for medical students the next year and she will include materials from the notebook in the curriculum.

## **4. Recommendations**

### *Marketing to Increase Referrals*

1. Provide ongoing information about the Transition Consultation service to Services Coordinators to increase referrals. Provide them with more information on the benefits of this service and the importance of early planning.
2. Periodically, conduct a survey of A & D Waiver Services Coordinators serving youth of the target age range to find out if they have discussed this service with the youth and families they are serving and what the responses have been. When this was done by HHS in February 2007, the number of referrals seemed to really increase.
3. Consider broadening the future planned scope of the clinic to include young adults on Medically Handicapped Children's Program.

### *Continue Physician Training*

4. Consider continuation and expansion of the physician's education component to build the capacity of physicians to serve youth with special health care needs in the future.
5. The Physician Notebook is being converted to DVD and a dissemination plan is being developed.

### *Evaluate Effectiveness of Pilot Second Visit*

6. Identify funding to continue transition consultation service to provide an opportunity to further implement the second phase of the consultations and evaluate its effectiveness.

### *Dissemination of Resource Materials for Youth and Families*

7. Consider placing the youth and family materials on transition on a website and/or DVD per recommendation of the National consultant.

## Appendix A

Consumer Feedback  
Services Coordinator Feedback  
Physician Feedback

## Consumer Feedback

### Most Helpful about the Clinic

That she is getting the help she needs.

I really liked how everyone addressed our son and talked to him about his care.

I already had much of the information that was provided, but thought that it was helpful to have them re-evaluate my son.

There was enough time to get all of my questions answered.

The group was caring, was able to get right to the point.

Overall it was wonderful.

Staff gave information and recommendations that will be helpful in planning for transition.

Simply knowing that there are friendly resources and sources of information. We are happy with the services we receive and know that we will always be treated well and receive information if and when necessary.

That I was seen by so many doctors.

Liked better than CP clinic. Liked having separate evaluations. I shared a copy with my teachers.

Actually talked to son and included him and he is excited about going back.

The staff.

Most of the people associated with the clinic were kind and helpful. The Consumer/Family Advocate, in particular, was personable and helped by sending literature that was informative.

They covered all areas. We really didn't know what to expect, but we were very impressed!

The resource book.

Discussing youth's needs. Not feeling like a lost parent or bad parent. My son felt very good after session.

Listening to our problems.

Talking to people who cared for me.

### Areas Targeted for Improvement

None that he can explain or think of.

Students need to introduce themselves.

No need to improve.

Some of the medical information was hard to understand.

Nothing.

Explain what is going to happen. Give me the report as well as the staff.

Not so early in the morning.

Would like them to get him a lap top.

We were unhappy with one of the Transition team members because of his line of questions and a comment he made.

Have the results and findings of the clinic given to primary provider quicker so changes can be implemented.

Get more info to the parents somehow. Youth needs somebody to hear them.

Help other kids with special needs at school.

## Services Coordinator Feedback

### Most Helpful about the Clinic

The notebook was great and all the concerns of the family were addressed.

I did not attend the clinic with my family but was very impressed with the thoroughness when I received the report and with the follow-up after the family came home. I think this is awesome to help our kiddos go into the adult world. Thank you for what you are doing and keep up the good work.

Informing the family of the need and availability of their future health care decisions.

The holistic and multi-disciplinary team approach to the youth's medical, social, vocational, and educational needs. I was glad to see pharmacology review the medications and enter into a discussion with the parents. The handouts and resources gathered ahead of time were impressive. I did visit with the parent after the Clinic. She shared that she was working on the "workbook" that was given her. It was specific to the youth and his needs.

The college information sent to the family was probably most helpful. This family is very self directed.

The medical recommendations offered were very helpful. I'm looking forward to the written report. For clients who are getting ready to enter DD services and don't have a Services Coordinator I think the other recommendations will be very helpful.

### Areas Targeted for Improvement

Not to have the psychiatrist first. I think the family would have been more comfortable with him later.

N/A at this time.

Would there be any way to shorten the time the family had to spend at the clinic? It was a long time for the youth, who has autism, to spend in strange surroundings. He did well. Scheduling clinics on non school or work days might have helped the family as well.

The family was very unhappy with one of the transition team members due to the line of questions asked and one comment that was made.

The only part of the clinic I didn't care for was the interview portion with the different clinicians, when the one-way mirror was used. I understand that some persons may be more comfortable in a smaller group and may not want to repeat answers, but I didn't feel comfortable knowing.

## Physician Feedback

### Most Helpful –Resource Book

Contact Information.

### Most Helpful-Clinic

Seeing the process of care with multiple providers-

Just the fact that it is a comprehensive list of resources that I can readily access.

Resource section and the transition guide for teens and parents.

Training medical students.

The resources.

Hard to narrow down, but probably the listing of services available and their contact information.

Excellent resource for background information regarding all of the needs of these kids and problems that occur when transition does not go smoothly. The timeline is very helpful to get patients/families/physicians thinking about and preparing for the future. The list of resources is very helpful. (without the help of a social worker, I would have no other way of knowing that these resources are available).

The transition health care assessment gives a good idea of functional status and concerns.

One Page Portable Medical Template - excellent, concise overall history. I like the info at the top of the sample that includes intelligence level, communication issues/etc. , as well as, the medical info. Overall excellent resources for personal training in this area, and for training residents.

Coordinated.

The overall orientation. The topic wasn't something I normally think about, so the orientation was helpful.

The huge list of resources!

To see all the resources available and to gain some knowledge about the transition process.

Experiencing the significant outreach capabilities of the program and seeing how it all interfaced.

Seeing how it works and meeting the people involved-which removes basic unknowns that could impair referral.

Seeing how the multidisciplinary approach works so well for these kids, and seeing what it all involved in the transition. I liked the summary "Youth Transition Plan". This would be very helpful to me as a provider when taking over care of the patients. One thing that would be helpful for me in the "Youth

Transition Plan" would be a little information about the individual's life expectancy/disease progression if applicable. And PT/OT did not seem to be very involved in the process.

Some sort of social work support would be very helpful for the providers and patients!

Thanks for the opportunity to be involved and learn about this important process.

## **Recommended Additional Educational Activities**

Executive summary for primary care doctor; Hot list of phone numbers.

Identifying autism earlier and Asperger's.

Info on state assistance programs (definitions/purposes/qualifiers).

Updates on the clinic, services, etc., as they become available. Thanks! Great Job!

Periodic lectures to the department for continued reinforcement.

**Transition Materials & Resources  
For Teens and Their Families  
Transition Consultation at Munroe-Meyer Institute**

**Add youth's name here  
Revise to individualize the notebook for the Youth  
Table of Contents**

1. Transition Planning

- a. *Transition Timeline for Children and Adolescents with Special Needs: Developmental Disabilities or Chronic Illnesses/Physical Disabilities*
- b. *Transition to Adulthood Timeline: Specifically for Nebraskans*
- c. *Ten Tips that may help ease your child's transition to adulthood*
- d. *Transition Top 10 List for Families*
- e. *Transition Planning Outline*
- f. *Transition Services for Students with Disabilities*
- g. *NICHCY – Transition Planning: A Team Effort*
- h. *Supporting Dynamic Development of Youth with Disabilities During Transition: a Guide for Families- article*
- i. *Thinking about Tomorrow - articles from a parent newsletter*
- j. *Parent Brief – Parenting Post-secondary Students with Disabilities: Becoming the mentor, advocate, and guide your young adult needs*
- k. *What Does Health Have To Do With Transition?*
- l. *Staying Healthy for Youth & Teachers*
- m. *Success at School Involves You, School Meeting: Your Role in Making Them Work*
- n. *Improving Communication: Action & Results*
- o. *Graduation Options*
- p. *Web Sites of Interest to Teens*
- q. *Some “Transition” Web Sites*

2. Health Care Transitions

- a. *Information for Teens and Young Adults*
- b. *Health Care Transitions Planning*
- c. *Appendix A: Questions to Ask Potential Adult Care Providers*
- d. *Appendix B: Paying for Health and Medical Care*
- e. *Appendix C: Health Care: A Transition Topic of Learning?*
- f. *Appendix D: Substitute judgment Series*
- g. *Emergency Information Form*
- h. *One Page Portable Medical Template*
- i. *More detailed information on Insurance and Medicaid*
- j. *Getting What You Need at Your Doctor Visit*
- k. *Caring for Youth with Developmental Disabilities During Transition: Top 10 Things to Know for Providers*

3. Services & Resources That May Be of Interest:

- a. *Easter Seals Nebraska - The Transition Project: Helping Youth with Special Health Care Needs Prepare for Life as Independent Adults*

- b. *Accommodations in College*
- c. *College Planning for Students with Disabilities*
- d. *College Prep Book*
- e. *PTI Nebraska*
- f. *Nebraska Workforce Development*
- g. *Systems Desk Reference*
- h. *Resources for People with Disabilities in Nebraska*
- i. *Dr. J.P. Lord School - Tips for Parents of Children with Multiple Disabilities*
- j. *www.housing.ne.gov*
- k. *Adapting Motor Vehicles for People with Disabilities*
- l. *MOBY – Metro Area Transit Paratransit Service*
- m. *Promoting Self-Advocacy Skills for Students with Disabilities*

4. *A Transition Guide for Teens & Parents: It's Your Future Go For It!*

5. Misc.

- a. *It's My Choice...Guides and Checklist to help people plan for the future they want, Minnesota Governor's Council on Developmental Disabilities*
- b. *IEP and Transition Planning Packet-MMI Media –written materials, forms, workbooks, and CD to help youth become an active member of their IEP team by MMI*
- c. *Personal Interest Inventory – Dr. John Holland-career interest inventory*
- d. *Holland Personality Types & Self Assessment*
- e. *What do I what to do? – Independent Living Institute*
- f. *JaxHATS – Transition Readiness Checklist*
- g. *AMA – Guidelines for Adolescent Preventive Services, Adolescent Questionnaire*
- h. *AMA – Guidelines for Adolescent Preventive Services – Parent/Guardian Questionnaire*
- i. *Planning for the Future*
- j. *Positive Student Profile*
- k. *Transition Worksheet*
- l. *My Future Plan*
- m. *Easter Seals Publication Products*
- n. *Transition Services Planner – Nebraska Department of Vocational Rehabilitation*
- o. *Health and Medical Issues for Transition-age Adolescents with Disabilities &/or Health Care Needs: A Guide for Teenagers and Their Families- Work book to help families and youth transfer the management of health care from the parents to the youth from LA*
- p. *Envisioning My Future-Workbook designed to help youth assess what skills they have to manage their own health care and learn the skills they do not have, from FL*

6.

7.

8.

Supported in part by a federal grant awarded to the Nebraska Department of Health and Human Services from the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (11-P-92578/7-01).  
Revised 8/3/07

**Munroe-Meyer Institute  
University of Nebraska Medical Center  
Transition Consultation  
Youth Transition Plan**

Youth's Name:	Date: MM/DD/YYYY	___ Initial Visit: Interdisciplinary Assessment
Parent(s)' Name:		___ Second Visit: Transition Planning
Team Members: Shirley Dean Sandy Houser Dr. Jennifer Parker Dr. Mark Fleisher Dr. Howard Needelman Tina Sedersten		Role: Family Advocate Clinical Nurse Specialist Internal Medicine-Pediatrics Psychiatrist Developmental Pediatrician Navigator

**Current Services:**

School	1. Youth plans to graduate from high school at age X or in 20XX. For youth with Developmental Disabilities, youth needs to plan to stay in school program (transition program) through the school year in which they turn 21 years of age. 2.
Health	1. Continue with current health care provider (name), until the time of transition, if applicable. 2. Continue with each specialist, include names, until the time of transition, if applicable. 3. Continue with current dentist (name) until the time of transition if applicable.
Social or Community	4. Continue with current social or recreational activities.

**Short Term Action Plan**

Plan for High School			
Steps	Person Responsible	Updates After First Transition Visit	Update After Second Transitions Visit

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Plan for Accessing Community Services			
Steps	Person Responsible	Updates After First Transition Visit	Updates After Second Transitions Visit

Plan for Accessing Health Assessments and Services			
Steps	Person Responsible	Updates After First Transition Visit	Updates After Second Transition Visit

**Future Long Term Transition Goals:**

Work/Financial	
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Health	
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Draft MM/DD/YYYY

Draft Revised MM/DD/YYYY



	9. A & D Waiver services currently received: child care, respite, and Medicaid.
Community	10. Continue to support J's participation in community recreation activities, especially those that involve physical activity: swimming through Special Olympics, Munroe-Meyer bike club and Camp Monroe, and outside activities with Mr. T.

## Short Term Action Plan

Plan for High School		
Steps	Person Responsible	Update
<ol style="list-style-type: none"> <li>1. Complete the IEP and Transition Planning Workbook for Home and a Positive Student Profile with J prior to next IEP meeting to assist in preparation for meeting.</li> <li>2. Discuss Results of IEP and Transition Workbook for Home with Family Advocacy to assess for needs and recommendations.</li> <li>3. Investigate options for increased services by occupational therapy and speech therapy in the education setting. Contact service coordinator at Westside Community Schools to determine eligibility requirements for increased services as part of IEP.</li> <li>4. Work with the IEP Team to develop J's Transition Plan within his IEP. Discuss with IEP team community resources that would benefit J and where to contact them.</li> </ol>	<p>J and family</p> <p>Family, J and Shirley Dean</p> <p>Family</p> <p>J and family</p>	

Plan for Accessing Community Services

Steps	Person Responsible	Update
<p>1. The family would like to learn about the services available through DD services providers:                      -Request information from the Health and Human Services, Developmental Disabilities Services, phone 595-2700. If interested, ask for the opportunity to tour services.                      -Information can be provided by Shirley Dean from the 2006 Nebraska Developmental Disabilities Provider Profiles, which gives information about each of the agencies that provide DD Services in Douglas County.                      -Mary Jane Austin agreed to provide the information requested by the family about waiting lists for services.</p> <p>2. The family is interested in residential services for Joe in about 10 years. Contact DD services in order to assure J's name is on the waiting list for residential services. Consider asking for in-home services as soon as possible and then 24 hour services by the future date that you want that.</p> <p>3. Assist the family in obtaining alternative respite services. Respite is paid for by the A&amp;D Waiver.</p>	<p>Family</p> <p>Shirley Dean</p> <p>Mary Jane Austin Family</p> <p>Claire Burton</p>	<p>1. Provided a list of agencies that provide Developmental Disability Services in the Omaha area, including their contact information. Discussed the process for obtaining services. (10/12/07 Shirley) The DDS Provider Profiles will be sent to the family.</p> <p>3. Provided information to Clare for the family on respite alternatives, as requested (Shirley 8/9/06). Discussed respite needs more on 10/12/07. Then talked to the MMI Recreation Dept, which provides an after school program (transportation would need to be checked with Westside), and a winter camp over the Christmas school break. This information was given to Clare for the T's. Mrs. T has checked on the respite provided by The Autism Center of NE, and this looks like it could be a good possibility. (11/2/07 Shirley)</p>

Plan for Accessing Health Assessments and Services

<ol style="list-style-type: none"> <li>1. Schedule formal audiogram to assess current hearing status at Boys Town National Research Hospital. Call 498-6540 to schedule appointment.</li> <li>2. Consider scheduling within 4-6 months screening tests for Metabolic Syndrome including blood for fasting glucose, hemoglobin A1-C and fasting lipids. Tests are indicated given his slightly heavy weight and high doses of medication. Test would check for negative side effects of the medication. Dr. Ralph Kramper can provide testing in his office.</li> <li>3. Consider scheduling an assessment for management of bed wetting with Dr. Brett Kuhn, Behavioral Psychology, if incontinence does not appear to be seizure related. Call Tammy Herring at Munroe-Meyer Institute; phone 559-5730 to schedule appointment.</li> <li>4. Genetics clinic consultation with Dr. Brad Schaefer is recommended to obtain further evaluation to assess for cause of eliptiform/cognitive disorder for planning for J's future, to optimize services available and to provide information for his biological siblings. To schedule call Deb Brumley at 559-6418.</li> <li>5. Blood studies to include Fragile X, DNA Micro array, chromosome 15 methylation studies and MECP-2 gene testing for genetics assessment with Dr. Brad Schaefer. Blood can be drawn by Dr. Kramper's office or schedule to be drawn at MMI by calling Sandy Houser at 559-4097.</li> <li>6. Request results of previous neuroimaging and laboratory testing done or sign a release form for MMI to obtain this.</li> <li>7. Consultation is available through Munroe-Meyer Institute Neurobehavioral Clinic regarding the medication Seroquel, to determine if there are other medications with fewer side effects and long term risks for side effects that J could take. Call Deb Brumley at 559-6418 to schedule appointment.</li> <li>8. Consider assessment with Adolescent Psychiatry to clarify diagnosis, behaviors, and evaluate lowest possible level of medications. Ritual behaviors should be monitored as he</li> </ol>	<p>Family</p> <p>J and family</p> <p>J and family</p> <p>J and family</p> <p>J and family</p> <p>J and family Or Sandy Houser J and family</p> <p>J and family</p>	<p>2. The family requested more information about this on 10/12/07, which was provided to Clare on 11/2/07. (Shirley)</p> <p>3. J remains incontinent for urine. Since his seizures cause the loss of his continence skills, we are not sure if this recommendation would be able to address this. (10/12/07 Shirley)</p> <p>4. J had genetic testing thru Dr. Andrew at age 8 or 9. Mrs. T will check to see if insurance will cover this. Shirley checked to see if this could be done at the second Transition visit. A separate appointment is needed. (10/12/07 Shirley)</p> <p>6. The T's will check on this (10/12/07 Shirley).</p> <p>7. The T's asked for more information on this (10/12/07 Shirley). Added information provided to Clare (11/2/07 Shirley)</p> <p>8. The family is interested in this and asked if it could be done at the</p>
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<p>ages to be sure they do not interfere with his ability to participate in community activities. Dr. Mark Fleisher 354-6370 for appointment.</p> <p>9. Find out status of J's eligibility for the children's mental retardation waiver which was pending based on HHS Healthcare Plan.</p> <p>10. The family indicated that they need to find a new physician for J 3/07.</p>	<p>J and family</p> <p>Family</p>	<p>second visit. Shirley checked and found that a separate appointment is needed. (11/2/07 Shirley)</p> <p>10. The team compiled a list of adult physicians who would be excellent providers for J. List given to Mary Jane for the family (Shirley 3/14/07 )</p>
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**Future Long Term Transition Goals**

<p>Personal/Work/Financial</p>	<ol style="list-style-type: none"> <li>1. J will apply for SSI just prior to turning 18.</li> <li>2. Determine need for a substitute decision maker for J when he turns age 19.</li> <li>3. J will transition to work that he enjoys with sufficient support to successfully learn a new job and to continue to learn work skills beginning in the spring of 2011.</li> <li>4. J will receive residential services in the community through the Developmental Disability Services system, when determined appropriate by his parents and possible through the DDS system.</li> </ol>
<p>Health</p>	<ol style="list-style-type: none"> <li>5. J will maintain optimal health to prevent secondary health care complications. The family is working on find a new adult doctor to serve J. Continue to see Dr. Raymond Crossman, ophthalmologist and Dr. James Pietro, dentist.</li> <li>6. J will have minimal seizures. Continue to see Dr. Andrews, neurologist.</li> <li>7. J will take only the minimum required medications for behavioral intervention.</li> <li>8. J will have medical insurance, hopefully, through Medicaid.</li> </ol>

Plan to be re-formatted

JT from Omaha  
 Date of Consultation: Nov. 2005

JT is a very pleasant 15-year-old

**DIAGNOSIS**

1. Intractable seizure disorder.
2. Autistiform behaviors.
3. Moderate mental retardation.

**TEAM RECOMMENDATIONS**  
 See Youth Transition Plan

## RESOURCES

A binder of resource information provided to the family included:

- I. Transition Planning
  - a. 10 Tips-that may help ease your child's transition to adulthood
  - b. Transition Planning Outline for Youth & Parents
  - c. Transition Services for Students with Disabilities-services schools are to provide
  - d. Transition to Adulthood-Services or contacts to consider by age
  - e. Graduation Options from the State Department of Education
  - f. Some Transition Websites
  - g. How to Find Community Resources- information about directories
  
- II. Health Care Transition Planning
  - a. Pediatric to Adult Health Care
  - b. Insurance and Medicaid
  - c. Health Care Skills and Teaching Tools, including working with Personal Care Attendants
  - d. Emergency Information Form for Children with Special Needs
    - e. Substitute Judgment Series-fact sheets from Nebraska Advocacy Services
  
- III. IEP and Transition Planning Workbook for Home and a Positive Student Profile

### Health Care Checklist

**This checklist is intended to help you plan for your transition to adult health care services. Hopefully, your responses will help you and your family identify areas to focus on as you prepare to manage your own health care more independently. Please check the box that best describes you and check if you would like to discuss this with the Transition Team.**

<b>I do not need to do this.</b>	<b>I do not know how but I want to learn.</b>	<b>I am learning to do this, but need more practice.</b>	<b>I do this.</b>	<b>I would like to discuss this with the Transition Team.</b>	<b><i>I plan to address this with my IEP Team.</i></b>
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**TO GET MEDICAL CARE, DO YOU...**

Call the primary care doctor's office to make an appointment?	<input type="checkbox"/>					
Make appointments for specialty care (i.e. orthopedist, cardiologist)	<input type="checkbox"/>					
Call the dentist office to make an appointment?	<input type="checkbox"/>					
Arrange for your ride to medical appointments?	<input type="checkbox"/>					
Keep a calendar or list of medical and other appointments?	<input type="checkbox"/>					
Complete medical history forms including a list of your allergies?	<input type="checkbox"/>					
Have a copy or know how to get a copy of your medical records?	<input type="checkbox"/>					
Call the doctor to tell him/her when you feel sick or have changes in your health?	<input type="checkbox"/>					
Understand and describe your medical condition or disability?	<input type="checkbox"/>					
Ask questions of the doctor, nurse or clinic staff?	<input type="checkbox"/>					

Answer questions from the  
doctor, nurse, or clinic staff?  
*Hire personal care assistants,  
train, and supervise them?*

**I do not need to do this.**

**I do not know how but I want to learn.**

**I am learning to do this, but need more practice.**

**I do this.**

**I would like to discuss this with the Transition Team.**

***I plan to address this with my IEP Team.***

**TO MANAGE MEDICATIONS AND MEDICAL SUPPLIES, DO YOU...**

Fill a prescription if you need to?	<input type="checkbox"/>					
Describe what medication you take and why you take it?	<input type="checkbox"/>					
Tell the side effects or bad reactions of each of your medications and what to do if you have a bad reaction?	<input type="checkbox"/>					
Take your medication correctly?	<input type="checkbox"/>					
Use and take care of medical equipment and supplies?	<input type="checkbox"/>					
Call the suppliers when there is a problem with the equipment?	<input type="checkbox"/>					
Pay for or arrange payment for medication, medical equipment and supplies?	<input type="checkbox"/>					
Reorder medications and medical equipment before they run out?	<input type="checkbox"/>					

**TO MANAGE HEALTH INSURANCE, DO YOU...**

Know what your health insurance covers?	<input type="checkbox"/>					
Carry your insurance card?	<input type="checkbox"/>					
Apply for and/or use SSI or Medicaid?	<input type="checkbox"/>					
Have a plan for health care coverage as an adult?	<input type="checkbox"/>					
Know how to apply for health insurance if needed?	<input type="checkbox"/>					
Understand how to keep your benefits while working?	<input type="checkbox"/>					

*Know how your medical care will be paid (i.e. self, insurance, Medicaid, Family, Trust)?*

<b>I do not need to do this.</b>	<b>I do not know how but I want to learn.</b>	<b>I am learning to do this, but need more practice.</b>	<b>I do this.</b>	<b>I would like to discuss this with the Transition Team.</b>	<b><i>I plan to address this with my IEP Team.</i></b>
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**TO MANAGE SELF HEALTH CARE, DO YOU...**

Do self-care activities to promote health (Ex. exercise, eat healthy, etc...)?	<input type="checkbox"/>					
Participate in your community by doing things like visiting the library, going shopping, or going to church/temple.	<input type="checkbox"/>					

**TO MANAGE JOB OR SCHOOL, DO YOU...**

Know your interests, skills, strengths?	<input type="checkbox"/>					
Know the services the school is to provide you to help in transition to adulthood?	<input type="checkbox"/>					
Know your education goals on your transition plan (IEP)?	<input type="checkbox"/>					
Receive career guidance from teachers at your school?	<input type="checkbox"/>					
Have or know how to request accommodations you need at school or work?	<input type="checkbox"/>					
Feel satisfied with the services you receive at your school?	<input type="checkbox"/>					
Apply for a job, work or obtain vocational services?	<input type="checkbox"/>					

**TO MANAGE DAILY LIVING, DO YOU...**

Explore living options (i.e. independent living, parents, other family members, campus/dormitory, long-term care facility, friends, group home)?	<input type="checkbox"/>					
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Advocate for yourself?	<input type="checkbox"/>					
Care for personal needs?	<input type="checkbox"/>					
<i>Arrange for transportation or understand how to use public transportation (bus, taxi)?</i>	<input type="checkbox"/>					

	<b>I do not need to do this.</b>	<b>I do not know how but I want to learn.</b>	<b>I am learning to do this, but need more practice.</b>	<b>I do this.</b>	<b>I would like to discuss this with the Transition Team.</b>	<b><i>I plan to address this with my IEP Team.</i></b>
Use a credit card?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Write a check or use a debit card?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use a savings account?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Make financial decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Plan to and understand how to apply for benefits at age 18?</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Adapted from University of Florida's Health Care Transition Initiative JaxHATS Evaluation Tool. Revised by Munroe-Meyer Institute and the Nebraska Department of Health and Human Services. Supported by a federal grant awarded to DHHS from the U.S. Department of Health and Human Services, Centers for Medicare and Medicare Services (11-P-92578/7-01).*

Physicians Training Curriculum and Resources  
On the Transition From Pediatric to Adult-Based Health Care  
For Youth with Special Health Care Needs

Table of Contents

1. Transition From Pediatric to Adult-Based Health Care for Youth with Special Health Care Needs Overview
  - a. Introduction
  - b. National Climate
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  - b. DVD's
    - i. *Health Care Transition: Jim's Story*. Institute for Child Health Policy, University of Florida. <http://video.ichp.ufl.edu>.  
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**Healthy & Ready to Work MODELS Project**  
***Interview with Katie Godshock - Ohio***  
***Interview conducted on January 18, 2008 and January 28, 2008***

*Cincinnati Children's Hospital Medical Center*

**Background**

Into sixth year of operation. End of 2008 is sixth year (started mid-end 2002)

I was not here at beginning, only here for about a year. Started off with a grant. Lucky to be housed in Cincinnati Children's Hospital Medical Center.

Spin-off of grant received through "lend". Believes every state is eligible for lend money.

Department I work in originally CCDD Cincinnati Center for Developmental Disabilities. Part of U of Cincinnati. Docs were employees of University. Come here, we'll diagnose you, then out to community for services.

CCDD housed at hospital, but were own entity. U of Cincinnati then disaffiliated with big general hospital in Cincinnati. Employees became their own, University hospital became their own. When that happened, CCDD not a good fit because big general hospital all adult hospital. So then linked up with Children's to become developmental pediatrics.

Moved from strictly diagnostic to diagnostic and treatment (had benefits of affiliation with hospital)

Only about ten-fifteen years a diagnostic and treatment center.

When that happened, got lend grand, because affiliated with hospital. Many things opened up – kids could be referred to psychologist, occupational therapy, etc could be internal referral and have normal wait time as opposed to bottom of list as outside of referral.

Location didn't change, but a lot of services opened up.

Big push to provide services to young adults – through lend grant, juniors in high school, anywhere from 15 years old through 60 years old (serve until successfully transitioned )

Dr. Webb – internist trained in adult medicine, pediatrician, did a neuro-developmental ped disabilities fellowship – adult and pediatric doctor.

**Development of Transition Program**

2002 – "We have a need" – Felt timing right to work on transition programs – because children aging out of children's hospital. When hit 21 or 22, children's don't want to see them. Families felt abandoned, "this is last time we can see you, good luck" – across the board, CYSHN and other children. Aged out, not a child anymore, didn't have equipment, services, etc to take care of adults.

Spina bifida clinic falls under developmental and behavioral pediatrics. Difficulty in medical part – anesthesiologist, orthopedic, they were adults. Sub specialties hung up on “they are an adult, we are children’s hospital” – didn’t know how to serve them.

Dr Webb was head of Spina Bifida clinic. Graduating kids from Spina Bifida program – needed shunt revised, spinal chord, etc, never established adult care, issues different, etc.

Then became clear that everyone needs primary care physician, and hard when only place you’ve been is children’s.

2000-2002 : “we need this” = transition

### **Planning**

Planning – unsure of planning process

2002 – decided that there would be three new adult clinics under Division Developmental Behavioral Pediatrics (already had Kelly O’Leary center, all autism, Cerebral Palsy clinic, Behavior clinic, Thomas center – down syndrome)

#### **Three new Clinics:**

- 1) adult down syndrome clinic - improve
  - 2) adult spina bifida clinic – had willingness to train - improve
  - 3) catch all “transition clinic” – anyone with developmental disability who had transition needs
- BRAND NEW CLINIC**

Screening process: any doc with patient over 15 would want to send to Dr. Webb and he couldn’t handle that volume

Through grant:

Full time Public health nurse, working with families – Tina

Half time social worker – Peter

Marcy Mendleson – employed through project search – help developmentally disabled find proper placement after school, some of her time dedicated to clinic, she is the school guru, what to do after school. “Between her and the social worker, very very good at what they do.”

Tina came up with pre screening questionnaire to see if transition clinic really what you needed.

Some families had lots of resources who just didn’t need a lot of help.

Worry that all 12 ped would send kids to Dr. Webb when might not need to.

1500 come through doors with autism – just autism

Goal of 500 kids

Dr. Webb only clinician.

Teaching hospital so also have fellow or resident.

See patients weekly, Wed, see four to five patients in five hour block. One hour per patient.

### **Transition Plans**

Peter and Tina developed questionnaire -- Started only taking internal referrals, mailed to families home, families sent it back, Peter and Tina did screening process. Every family that was referred got a questionnaire. Lots of phone interviews. Because in a tri-state area, not feasible to meet with families face to face. Families mail survey back, Tina calls them, asks what they are looking for, i.e. Dr Webb is not psychologist, will we meet your needs? Some families said no. Made lots of referrals to adult primary care outside of Children's. Families were comfortable with that. A lot of families loved idea, wanted to see Dr. Webb, had lots of issues that they brought. Some families already had developed transition plans,

#### **Areas transition clinic to help on:**

- 1) pediatric to adult care
- 2) school to work or placement
- 3) parent home to living on their own, or if something happens to parents
- 4)

Some families didn't need all that, already had plan, just needed primary care physician. Involved educating primary care providers what transition clinic was – didn't necessarily need them to help kids get their meds, just had to make call to primary care doctor.

### **Relationship to University Hospital**

The residents in general pediatrics are in clinic at U of Cincinnati College of Medicine, out of University Hospital physicians office, where they get their primary care experience. Still a tie to "University Hospital". Big medical office building.

Resident in clinic with us, see patients, make recommendation to see primary care, Dr. Webb would say "well so and so is at University and can see you"

Great for families in this area – downtown, 15 min radius. Then people hear about us, requesting referrals, we're growing. Tri-state area, Ohio, Kentucky and Indiana.

Families who liked adult doctor living in Indiana, 40 min away, but needed help with school transition.

### **Input from Families**

In rural areas, have the family practice "I still make house call docs."  
Learned about adult docs from families in rural areas.

Hardest part transition from pediatric care to adult care. Marcy and Peter are good, so trying to milk relationships with outside docs to continue to see them.

Unanticipated homework assignment – building network of adult providers outside metropolitan area. Anticipated we would need to work hard with adult specialists, but didn't think we'd have as much difficulty with primary care. Now, from our perspective, things are a lot better – have docs to refer to, docs set up practices after residency, families willing to drive. But goal is to have primary care close to families in remote areas.

Sometimes families call after referred and say they don't like the doc. Sometimes docs not accepting new patients. Always looking for new docs to provide primary care. Willing to write scripts, etc. Either family practice or internists. We found that both are willing, doesn't matter trained as FP or internists.

Not resistance in seeing them, but resistance in writing scripts that are typically written by psychiatrists. A lot of behavioral kids on meds – antipsychotic. A lot of primary care won't write for those, and tell them need to drive to psychiatrist. Hard to convince doc in rural areas to use meds. **A lot of it is providing education to primary care physicians.**

Understand where they're coming from because weren't trained in these medications.

### **Clinic**

Meet every wed from noon to 7 or 8

Katie is ped nurse practitioner. – took Tina's place. Tina still does adult Down syndrome and Spina Bifida. (other two new ones) Katie can bill insurance and Tina cannot. Larger demand than slots to see kids in transition, needed more providers for down syndrome and Spina Bifida.

Renee Rodriguez in last year of fellowship, staying on to do transition, will have similar training of Dr. Webb. Ped trained in neuron developmental/behavioral pediatrics.

Monday – transition team meeting for two hours, go over anyone who has called, needed paperwork filled out, shown up at clinic, etc. usually a teaching piece as well, new waiver, etc. what does this mean for us? Spend a lot of time talking about patients.

A lot of patients on yearly check in basis. Successfully transitioned from school to work or some type of day program, or not living at home anymore, or have a plan for what happens when mom and dad aren't here. Come to clinic for meds. Seeing adult provider who can't write for meds, so need to come to clinic for meds.

### **Patients**

20% are the yearly “med check” people – really stable.

Now seeing new patients, scheduling into March. But if call with a crisis, can fit you in.

Not medicine pushers, really into weaning meds down, but find that some kids just do better on some meds.

Remaining 80% seen every three months. Some are monthly.

Six month guys – for med increases check in.

If graduating, need to update plan, things are in the works. Young adult might be stable, but things come up that need to check in about.

Three months – young adults actively doing something – starting new med, changed where living, graduated and need to see how job is going, etc.

Once a month – new patients, given an assignment, file paper work, follow up

## **Documentation**

Marcy writes transition plan, dictate physical exam.

Recommendation – family came in for initial visit, these are our concerns, here are our recommendations. Families get copy of dictation, can flip to recommendation/assignment. Med calendars so can see if they have to wean on and off. Books on guardianship. Keep substantial stack of paperwork for different counties so can start filling out on the spot. Here are forms for SSI, here's website, every county is a little different.

Fifty Fifty split, some families need a lot of handholding – I called your prescription, be sure you pick it up. Other families just need the plan, come for next visit.

## **Barriers**

Literacy an issue. Personally, have more functionally illiterate families than we realize. We have it on our radar screen to address. We see kids with autism, asbergers, Fragilex genetic syndrome gets worse as generations go on, mom might have it too, child condition magnified.

\*\*\* VERY lucky to be under umbrella of Children's hospital. Can find interpreter. Also benefit from economies of scale, appointment making, billing, etc.

Because so big, take EVERY insurance.

Don't have administrative person for the clinic.

RN's take height weight BP to great families. (8, but divided into teams of 2)

PCA – patient care assistant.

Visit is not very medical, very counseling based.

For next call:

How is clinic paying for itself, staff salary, etc.

More about evaluation/feedback

Collaborate with OH title V

Email blank docs?

Numbers served?

Barriers

Hot Tips

Now can take people from outside children's.

## **Follow up with Katie 1/28/08**

See patients one day a week on Wednesdays

Internal referrals nice in theory, but didn't last long.

Phone intake comes in with self referrals. Had to be done quickly because patients were coming.

Defeat autism movement, testing waters with transition clinic.  
Kelly O’Leary center – totally separate, not part of planning process. Refer to transition clinic.  
Before me, Tina, and Dr. Webb, didn’t want to handle load of more than 500.

Now patient load is approx 500.

Ready for new patients now.

Try hard to graduate people, but also a security blanket for a lot of parents. What will happen if we leave?

\*\*\*Could use improvement in transitioning OUT of clinic.

Goal is more than 500. Jumping from one provider to three (Dr. Webb, Katie, Renee Rodriguez).

Katie been seeing patients for a year with Dr. Webb (in March will be on own)

Katie will have a lot of days through the week.

NP – can’t be initial visit. Medications that I can’t prescribe. I will fit in as maintenance, people already on medicine, more resources less meds, etc. Counseling end of things.

Wednesday still heavy day, see new patients. Dr. Webb, me and Renee all there. Hoping to keep it that way. Opportunity for youth to have all five providers available to them. Parent come to appointment with pre-screening questionnaire already filled out.

Wednesday new clients – tough cases. Can split up for the yearly/monthly visits. New patient will get all 5 providers, hope they have already filled out questionnaire. Most of the time they have.

Would want to keep breakdown, if we are doing out job (1 month, three month, etc.) if gets too far from the 20% 80% breakdown, will need to re-evaluate what we are doing, what patients we are seeing, etc.

### **Barriers**

Families can’t find people to prescribe meds, then get to transition clinic, get meds, finally someone to help them. Becomes safety net.

Tweaked the way “graduate” the clinic – if you’ve been a patient, open door safety net. Hopes that won’t see them in 5 years. Goal is to transition them, jumping off point into adult medicine.

**Didn’t have any idea how hard that would be – to find GOOD ADULT CARE.** Problems confounded when move to rural areas. Get rural pretty quick.

Being in tri-state area, all Developmental Disability boards are by county. Hamilton County (where we are, has good services).

Dr. Webb has built adult network beyond metro areas

Peter has lots of contacts

Marcy also goes to schools

Peter and Marcy not tied down to county like the providers.

Talk to Tina re: planning process

Aging out, not necessarily too complex, of Cincinnati children's hospital. Become adult problems, so not their specialty.

**Can refer to Med Peds docs – like Dr. Webb**

**Rare, not many docs are dual certified.** Rare in our area.

\*\*\*Opportunity for Med-peds physician is AMAZING. A great fit.

### **Prescribing Medicine**

Transition from school, into adult, etc, can enhance behaviors that might not have been treated before.

Parents had tried psychiatrists to prescribe behavior meds/traditionally psych meds for adults. Psych aren't best fit – try to work through problem – kids with behavioral disabilities might not be able to work through it the way a psychiatrist would. Anxiety, behavior issues, parents are stuck.

We get them on meds to help with behaviors, then can help them set up plan. Wean them off meds, when set up with adult doc, ask them if they can prescribe – becomes education piece for doctors. “been on this stable dose for 3 years, these are side effects, etc”

Easier to talk to physician than block out an hour to see patient to do med.

Counseling model verses med on an individual basis.

Some kids really just need help school to work, etc. Some other kids are heavy medically.

Sometimes clinic all medical, sometimes all counsel. Healthy mix of both.

\*\*\*Never a visit where we DON'T COUNSEL. Always say “hows school, what's the plan, hows work” – ask about transition plan.

Title V – spina bifida clinic BCMH (bureau for children medically handicapped) tied to title V

Transition clinic – not closely tied to title V

Title V has presence in hospital – Spina Bifida clinic.

Molly – service coordinator, deals with kids 12-21. Transition coordinator for kids with Spina bifida, through title V. 15 year old with Spina Bifida, comes in to Spina Bifida clinic, ages to adult Spina Bifida clinic, paid for by title V.

Takes any insurance.

Half private, half public (Medicaid, choose carrier)

Many that start private become public because age off parents.

75% of under 18 year olds have parent's insurance, but Medicaid as back up.

Remaining 25% BCMH.

Kids with seizure, can't figure out how to do billing – usually denied.

Age when come in – depends how they are coming. If referred from our department, in our division, usually end of high school (17 or 18)

Have had plenty of kids.

After transitioned, i.e. successfully have primary care provider, say don't make another appt, just make another appointment if you needs us. Just call if you need us. If we've seen you three years, stable, etc, just call us. If something complicated, then have them come in. We insist they have adult provider, but don't worry, you can call us. (Have tweaked it because parents get panicky) Rare that they see the 25 year old again.

We are never primary care provider, have already set them up with primary adult provider, have transitioned, etc. ask them "have you been to your primary care provider"?

Transition is tough, have to be comprehensive.

Every visit is billed, so clinic can pay for itself.

### **Evaluation**

Evaluation process: Parent advisory committee. Periodically have done quality surveys via survey monkey. Hard because not everyone has internet access. Depend on the parent advisory committee. Hospital wide. Our division has one that meets monthly.

Out of the meetings came a portable health notebook. Came from our parents saying "we would have kept better track"

Notebook - Big binder that keeps ongoing health info...meds, study, surgeries, etc.  
By educating parents in transition clinic, they have gone and educated other parents.  
Division of developmental and behavioral pediatrics.

Nice because wide range of parents. Sometimes have speakers, different every month.  
Work with Spina bifida assoc of Cincinnati.

### **TIPS/barriers \*\*\***

**Start early –Can do better work with a 14, 15 year old than a 22 year old.**

Lots of services are easy to get when in school, not as easy after have graduated  
Ideal clinic starts at age 13 yrs. Doesn't have to be real intensive, just put a bug in parents ears (not going to be in school forever, etc.)

Parents can be their own worst enemy. Parents who have always done everything for their children, all of a sudden 65 yrs old and is hard.

\*\*\* encourage independence. Have to let children be as independent as possible. We have recommended family counseling.

\*\*care giver burnout – especially with CP kids, tube feedings, etc. Ask parent/caregiver "how are you doing, do you get support, etc"

\*\*size of physical layout is barrier – tight, not developmentally friendly. Building for division is being built. Now it's a hurry up and wait thing.

\*\* need to prove it, have done that.

Will think about hot tips

Autism has grown because many visits can be billed.



Legal Guardian:     same as person you live with     self     other

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ County: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone Number \_\_\_\_\_ Relationship to you \_\_\_\_\_

Other person(s) to be notified of your appointments:

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

Telephone \_\_\_\_\_

## **HEALTH HISTORY**

What is your disability? \_\_\_\_\_

Do you have any other health conditions? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Your usual health is     Excellent     Good     Fair     Poor

Do you have any special concerns or issues you would like to talk about at this visit? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What do you hope to learn from this appointment? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Check all that apply to your health history

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> Head injury              | <input type="checkbox"/> Vision problems   | <input type="checkbox"/> Teeth problems                 |
| <input type="checkbox"/> Crossed eyes             | <input type="checkbox"/> Headaches         | <input type="checkbox"/> Problems chewing or swallowing |
| <input type="checkbox"/> bleeding problems        | <input type="checkbox"/> Spasticity        | <input type="checkbox"/> Nutrition problems             |
| <input type="checkbox"/> Hearing concerns         | <input type="checkbox"/> Seizures          | <input type="checkbox"/> Weight concerns                |
| <input type="checkbox"/> Ear infections           | <input type="checkbox"/> Sleep problems    | <input type="checkbox"/> Diarrhea                       |
| <input type="checkbox"/> Heart problems           | <input type="checkbox"/> Urinary problems  | <input type="checkbox"/> Constipation                   |
| <input type="checkbox"/> Lung problems            | <input type="checkbox"/> Kidney problems   | <input type="checkbox"/> Abdominal pain                 |
| <input type="checkbox"/> Asthma/hay fever         | <input type="checkbox"/> back problems     | <input type="checkbox"/> Joint Problems                 |
| <input type="checkbox"/> Skin problems            | <input type="checkbox"/> Muscle problems   | <input type="checkbox"/> Attention Deficit Disorder     |
| <input type="checkbox"/> Autism                   | <input type="checkbox"/> Cerebral Palsy    | <input type="checkbox"/> Learning problems              |
| <input type="checkbox"/> Developmental disability | <input type="checkbox"/> Thyroid           | <input type="checkbox"/> Numbness or tingling           |
| <input type="checkbox"/> Chronic pain             | <input type="checkbox"/> Down Syndrome     |   |
| <input type="checkbox"/> Menstrual problems       | <input type="checkbox"/> Movement problems |   |

### **Family History**

Does anyone in your family have the following?

- |  |   |
|--|---|
| <input type="checkbox"/> High Blood pressure                 | <input type="checkbox"/> High cholesterol         |
| <input type="checkbox"/> Kidney disease                      | <input type="checkbox"/> Mental illness           |
| <input type="checkbox"/> Bleeding problems                   | <input type="checkbox"/> Asthma/hay fever         |
| <input type="checkbox"/> Diabetes                            | <input type="checkbox"/> Seizures                 |
| <input type="checkbox"/> Stroke                              | <input type="checkbox"/> Cancer                   |
| <input type="checkbox"/> Heart problems                      | <input type="checkbox"/> Developmental disability |
| <input type="checkbox"/> Inherited (genetic) medical problem | <input type="checkbox"/> Thyroid                  |

### **Medications**

What medication(s) are you currently taking? Please list dosage and the times you take the medication. \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Pharmacy: \_\_\_\_\_ Phone number: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip code: \_\_\_\_\_

Do you take any over the counter medications (such as vitamins, Tylenol, herbal supplements, melatonin)?  No  Yes If yes, please list dosage, frequency

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Do you have any allergies to medication and/or food?  Yes (please list)  No

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Are your immunizations (shots) up to date?  Yes  No  Not Sure

Who is your primary health care provider? \_\_\_\_\_

Date last seen: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip code: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Who is your dentist? \_\_\_\_\_

Date last seen: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

Phone number: \_\_\_\_\_

Do you see any specialists?  No  Yes If yes, please list name, specialty, address

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Where do you go when you are sick? \_\_\_\_\_

Where do you go for emergency care? \_\_\_\_\_

List any hospitalizations and/or surgeries you have had:

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Have you ever had any of the following?

- EEG, CT scan, MRI, X-rays     Yes     No

Date of most recent: \_\_\_\_\_

Where done: \_\_\_\_\_

- Psychological testing (Learning Evaluation) done     Yes     No

Date of most recent evaluation: \_\_\_\_\_

Where done: \_\_\_\_\_

- Audiology (Hearing Test)     Yes     No

Date of most recent evaluation: \_\_\_\_\_

Where done: \_\_\_\_\_

- Eye Exam     Yes     No

Date of most recent exam: \_\_\_\_\_

Where done: \_\_\_\_\_

- Speech Evaluation or Therapy     Yes     No

Date of most recent evaluation: \_\_\_\_\_

Where done: \_\_\_\_\_

- Chromosome /Genetic Testing     Yes     No

Date of most recent testing: \_\_\_\_\_

Where done: \_\_\_\_\_

- PT and /or OT     Yes     No  
 Date of most recent therapy: \_\_\_\_\_  
 Where done: \_\_\_\_\_
  
- Counseling:     Yes     No  
 Date of most recent session: \_\_\_\_\_  
 Where done: \_\_\_\_\_

**INSURANCE**

*(Please bring insurance card with you)*

Do you have hospitalization or medical insurance?     Yes     No  
 Name of Insurance Company: \_\_\_\_\_  
 Name of policy holder: \_\_\_\_\_  
 Policy or ID number: \_\_\_\_\_  
 Insurance medical phone number: \_\_\_\_\_

Do you currently receive assistance from any state, county or city agency?

- BCMH (Bureau for Children with Medical Handicaps)
- CHIP (Children’s Health Insurance Program)
- Medical Card (Medicaid)
- Secondary Insurance
- Supplemental Security Income (SSI)
- SSI-Disabled Children’s Program (SSI/DCP)
- Other \_\_\_\_\_

**EDUCATIONAL INFORMATION**

Are you in school now?     Yes     No  
 If not in school, are you a high school graduate?     Yes     No  
 Grade or class \_\_\_\_\_  
 Where? \_\_\_\_\_  
 School District \_\_\_\_\_  
 Phone number: \_\_\_\_\_  
 Teacher: \_\_\_\_\_  
 If in school, do you have an IEP or 504 Plan?     Yes     No  
 Date of most recent plan \_\_\_\_\_

Do you receive any of the following services at school?

- Speech therapy    How often? \_\_\_\_\_
- Occupational Therapy    How often? \_\_\_\_\_
- Physical Therapy    How often? \_\_\_\_\_
- Resource Room    How often? \_\_\_\_\_
- Classroom aide    How often? \_\_\_\_\_
- Job Training/Work Study    How often? \_\_\_\_\_
- Job Coach    How often? \_\_\_\_\_

### **OCCUPATIONAL INFORMATION**

Do you have a job?     Yes     No

What do you do? \_\_\_\_\_

Where? \_\_\_\_\_

How many hours per week do you work (on average)? \_\_\_\_\_

Do you have a job coach?     Yes     No

### **COMMUNITY**

Do you receive services from any of the following agencies: (if you do, please check box and write the name of your service coordinator and phone number)

- MRDD \_\_\_\_\_
- Bureau of Vocational Rehabilitation \_\_\_\_\_
- United Cerebral Palsy \_\_\_\_\_
- CITE \_\_\_\_\_
- BCMH \_\_\_\_\_
- Juvenile Justice System \_\_\_\_\_
- Other \_\_\_\_\_

revised 10/9/2003

## **INFORMATION**

Please check all information you would like to have:

- Mental Retardation/Developmental Disability Board (MRDD)
- Counseling/ Mental Health Services
- Medicaid/Health Insurance
- Transportation
- Support groups
- Transition
- Social Security/SSI
- School services/ IEPs
- Information about my medical condition
- Sexual Development
- Vision, Hearing evaluation
- Dental Care
- Bureau of Vocational Rehabilitation (BVR)
- Job information/career development/vocational evaluation
- Independent Living Resources
- Recreation and Fitness
- Community agencies
- Taking Care of Myself
- Self Advocacy
- Self Determination
- Wills and Guardianship
- Respite
- Assistive Devices and/or Technology
- Other \_\_\_\_\_

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Revised 10/28/2004

## Lifeskills Checklist

Skills at home	Can Do Already	Needs Practice	Plan to Start	Accomplished
<b>Kitchen:</b>				
Operate appliances (cook top, oven, microwave, toaster, dishwasher)				
Use common kitchen tools (can opener, bottle opener, knife, measuring cups and spoons, grater, timer, egg beater, ice cream scoop)				
<b>Help plan and prepare meals</b>				
Follow a recipe				
Put away the leftovers				
Set the table				
Do the dishes				
Familiarity with contents of packaged foods				
<b>Laundry</b>				
Put dirty clothes in hamper				
Sort clothes				
Use washer and dryer				
Iron				
Hand wash				
Fold clothes				
Put clothes away				
<b>With the Family</b>				
Watch TV news and discuss together				
Help take care of siblings				
Participate in family decisions				
Plan family outing				
Take care of pets				
<b>Housekeeping</b>				
Clean room				

Developed by the Youth in Transition Project (1984-1987) University of Washington Division of Adolescent Medicine and based on a Model developed by the Children's Rehabilitation Center at the University of Virginia.

## Lifeskills Checklist, Cont'd.

Skills at Home	Can Do Already	Needs Practice	Plan to Start	Accomplished
<b>Housekeeping, Cont'd.</b>				
Make the bed/change the bed				
Choose decorations for room				
Minor repairs (change light bulbs, repair or assemble toys)				
Take out the trash				
Basic sewing/mending skills				
<b>Gardening</b>				
Plant a garden				
Mow/water the lawn				
Weed the garden				
Learn appropriate use of garden tools				

<b>Emergency</b>				
Plan fire exits and emergency procedures				
Know where candles and flashlights are				
Use a fire extinguisher				
Know how to turn water off				
Know community emergency telephone numbers				
Know where extra house key is located				
Unclog the sink or toilet				
<b>Personal Skills</b>				
Use the phone				
Have a house key				
Budget allowance				
Go shopping				
Have privacy in the bathroom				
Manage personal grooming (shampoo, bath, shower)				

### Lifeskills Checklist, Cont'd.

<b>Skills at Home</b>	<b>Can Do Already</b>	<b>Needs Practice</b>	<b>Plan to Start</b>	<b>Accomplished</b>
<b>Personal Skills, Cont'd.</b>				
Get a haircut				
Choose appropriate clothes to wear				
<b>Health Care Skills</b>				
Understand health status				
Be aware of existence of medical records, diagnosis information, etc.				
Prepare questions for doctors, nurses, therapists				
Respond to questions from doctors, nurses, therapists				
Know medications and what they're for				

Get a prescription refilled				
Keep a calendar of doctor, dentist appointments				
Know height, weight, birthdate				
Learn how to read a thermometer				
Know health emergency telephone numbers				
Know medical coverage numbers				
Obtain sex education materials/birth control if indicated				
Discuss role in health maintenance				
Have genetic counseling if appropriate				
Discuss drugs and alcohol with family				
Make contact with appropriate community advocacy organization				
Take care of own menstrual needs and keep a record of monthly periods				
<b>Community Skills</b>				
Get around the city (pedestrian skills, asking directions)				

### Lifeskills Checklist, Cont'd.

Skills At Home	Can Do Already	Needs Practice	Plan to Start	Accomplished
<b>Community Skills, Cont'd.</b>				
Get around the city (pedestrian skills, asking directions)				
Use public transportation (taxi, bus, etc.)				
Locate bathroom in unfamiliar building (i.e. know how to ask)				
Know about neighborhood stores and services				
Use a pay phone				
Use a phone book				
Open a bank account				

Get a library card				
Get a picture ID				
Get a Social Security Card				
Use Post Office				
Volunteer for community services				
<b>Leisure Time Skills</b>				
Help plan a party				
Invite a friend over				
Subscribe to a magazine				
Read a book				
Plan a TV viewing schedule				
Go for a walk				
Join the Scouts, YMCA/YWCA, 4-H Club				
Go to a recreation center				
Go to camp				
Attend school functions (plays, dances, concerts, sports)				
Go to Church				
Keep a calendar of events				
Participate in a sport				

### Lifeskills Checklist, Cont'd.

Skills At Home	Can Do Already	Needs Practice	Plan to Start	Accomplished
<b>Skills For The Future-Education</b>				
Meet with school Guidance Counselor				
Check future educational options				
<b>Vocational/Technical Options</b>				
Contact school Guidance or DVR Counselor				

Check on local workshops/job opportunities				
Find out about apprentice programs				
Get information from community colleges				
Learn how to apply for a job				
<b>Vocational/Technical Options, Cont'd.</b>				
Check on local workshops/job opportunities				
Find out about apprentice programs				
Get information from community colleges				
Learn how to apply for a job				
<b>Living Arrangements</b>				
Be aware of federal housing regulations for the disabled				
Explore group homes and tenant support apartment living programs				
Find out about financial assistance programs				
Learn how to manage money and budget household expenses				
Understand leases				
Know the responsibilities of a tenant & landlord				
Know how to fill out an application				
Check for wheelchair accessibility if needed				
Look into transportation				
Know about services: electricity, phone, water				

**Healthy & Ready to Work MODELS Project**  
***Interview with Dr. Renee Turchi - Pennsylvania***  
***Interview conducted on January 3, 2008 and January 22, 2008***

***St. Christopher's Hospital for Children***

***EPICIC - Education Practices in Community Integrated Care***

Program funded as **Medical home grant as quality improvement initiative** in 2001- started in 2001 with nine practices. Since then, have worked with 60 practices, though some practices are more active than others, so number is closer to 50. Work with pediatric practice in 33 counties.

“24” at end of grant report. Constantly recruiting.

Medical home described as an approach to care, not a physical structure, but a way to provide primary care. Grant focuses on CYSHN/chronic diseases. All adults should have medical home. Emphasize patient-centered and family-centered care. Office has expectations of the family; family has expectations of the office.

**Quality Improvement**

Quality improvement piece might be gathering patient registries, improving efficiency, etc. In the QI genre, try to take small steps of change. Identify area to improve upon, employ different methodologies in practice setting to make small increments of change. Have advocated care coordination and transition to adult-centered care, have evaluation component. Then see did it make impact? Successes? Failures?

Important to recognize that the practices are all different. MH looks different in each place (not cookie cutter). Share information via conferences, teleconferences, etc. Next conference on transition to adult-centered care, will have 30-50 practices attend. People are at different stages along continuum.

**Why People Work with Dr. Turchi**

As project director, conducts initial assessment with practices interested in working with them. Sometimes practices who've heard about program come to her, or have an issue they need help with, or sometimes they have specific geographic areas to visit and see what they can offer.

Very different why people want to work with RT project—community resource piece, engaging parents, etc. When level playing field with the concept of MH, removing myths, can try to figure out the specifics they want to work on.

Want access to community resources, TA, linking to other resources, linking practice to practice. Linking like-minded folks together to integrate care.

### **Transition Program and Partners**

Transition has been PART of what they've worked on. Began to partner with pediatric chapter of family physicians.

Housed in Penn chapter of American Academy of Pediatrics.  
Get money from DPH; a lot of it is networking.

Partner with AFP – Academy of Family Physicians.  
And Penn chapter of AAP.

AFP Program to look at transition, foster MH in family practices. Three years ago, wanted to do needs assessment to see where the practices were. Conducted transition survey to practices in 2005.

Total of 24 practices that completed the survey. Very brief survey - 2.5 pages. Eye-opening - less than one third of practices had any formal program/policy for transition. More than ¾ wanted help with it.

**Barriers** – didn't know which family physicians to transition kids to. Reluctant to let kids go. Didn't want kids to go to adult providers. Felt lost knowing how to navigate adult arena – insurance, Medicaid running out, etc. Both parents and professionals needed help navigating insurance, vocational education etc.

### **Method**

Geographically linked family and pediatric physicians to provide access to care.  
Superimpose maps to link adult providers.

Now planning third conference devoted to transition to adult care – hands-on conference, face-to-face, as most effective mechanism to help practices work through issues. Bring in variety of people to go through important points – bring in people from the state to talk about insurance, state planning, state residential facilities, resources at county and state levels.

Broke down data for each practice, went through the data they'd (physicians and pediatricians working together) been collecting -- developed registries for all CYSHN, not necessarily transitioning.

Registry – lists DOB, wheelchair needs, insurance, etc. and assigned severity score. Went back to registries for each practice, pulled out all the kids 14 years and older, and divided patients by age groups.

14-15 yr olds needed to be starting transition  
16-17 second group  
18 and older in the practice

“**AH HA!**” moment – really helpful to look at the group of 18 and older that were still in their ped practice, “holy smokes!” need transition policy. Invited transition experts. Used as tipping point to see where to help transition program. Age 13 as where you should start transitioning, but used 14 so more manageable.

Matched up with geographic center.

### **Transition Conferences**

Will set up multiple tables at conference – always have lead physician, a nurse (sometimes care coordinator) always office manager/front desk person, sometimes social worker, and really helpful to have parent/youth representative. Having someone on consumer end was really key. Anywhere from 4-6 people working in the groups.

Use access database to generate reports on individual ped practices. If could pull insurance info, would be very helpful.

When possible and had family practices located in geographic proximity to pediatric practices, had them work together so they could be connected. Good opportunity for family practices to say to pediatricians, “this is what we’d need to see the kids...getting medical records signed...transition care plans...showed care plans to family physicians to see feedback.” Etc.

At second conference in 2006:

25-26 pediatric practices attended conference (50%)

7-8 family practices (about 1/3)

### **Funding**

Practices get funding from Dr. Turchi—don’t have resources to fund all practices, so not all funded. Of the 53 that have been active, have funded a total of (real time today) 33 practices at one point, at variety of different levels and different lengths of time. \$3000-\$10000 per year, sometimes multiple years. Their program has dual funding, so could fund multiple programs.

Funding them through “care coordination mini grants” – sort of QI, but some have used \$\$ to offset costs from transition efforts, some have used it to hire care coordinators, people have used funding for different things. Didn’t want to just hand out money, wanted people to be able to decide best use for them.

### **Next Steps**

Next conference date April 20<sup>th</sup> in Harrisburg, PA.

Want to hear what they put in place after conference (i.e., some recognize don’t have good records, some don’t have good care plans, etc)  
How pediatricians and families work together.

## **FOLLOW UP 1/22/08**

On brink of third conference on transition (April 20<sup>th</sup>, 2008)

Have conferences twice a year, every year since program inception 2001. This is the third conference specifically focusing on transition. Transition is a piece of what they do.

Did survey/needs assessment - Patti Hacket and Patience White helped develop needs assessment. 24 practices filled out survey.

### **As of today:**

There are 62 practices in total that we've worked with since 2001. Deemed them "medical home trainees" – all pediatric practices, including one family practice that has a pediatrician.

Of the 62, 39 are active "medical home adopters" – meaning they call in every month, come to every conference.

Gave survey out to 32 practices at a conference. 24 returned survey at the conference. Didn't do it at transition conference, did it six months before to see how to tailor to transition conference.

### **Other topics for conferences:**

Transition

Medical home -- go with the need...at first, might talk about what is a medical home, and then go into more detail

Cultural competency – have folks from national center \*good conference

Care coordination – from parent perspective, and practical aspect, how it works and how reimbursed

Parent and youth partners

### **Database/Registry:**

Access database has 10,000 kids in it. Not all practices are funded but registry is requirement for funding.

Always start with registry – need to identify the kids in your practice. Have found that practices have some type of registry going, and they help them tweak it. As go on, practices see benefit of tracking. Part of funding is to offset cost of coordinating care. In order to do that, need to have kids identified that need coordination.

Can choose which kids to focus on – based on what you want to accomplish, can identify certain kids i.e. most severe, those that need feeding tube, etc.

### **Funding:**

Need to be in the program for six months before get funding.

"In the program" = expressed formal commitment to what they are doing. A formal verbal agreement to start participating i.e. in teleconferences, conferences, etc.

Have had practices join that say major focus is transition.

Many times after start coming to conferences, realize the benefits.

Official once identified kids, have medical home team, etc. Don't want to give them funding until have a plan.

**Quality Improvement:**

Help them identify a registry – rural practices that don't use computers, look at how office is set up, excel spreadsheet. Practices have families sign off on HIPPA's. Severity score, track whether child needs home nursing, etc, help them track what type of insurance.

Practice has patient name column, but delete when send to Turchi.

**Use registry:**

To determine how much time and who the care coordinator should be in practice.

Able to sort based on diagnosis.

Resource nights – bring in different community providers/resources

Link registry to practice management system – can star those kids who are CYSHN – that way when Johnny Smiths mom calls for appointment, know that he is CYSHN and needs to meet for 20 min instead of only 10 min.

Can chose which kids to identify i.e. might not need 20 min with asthma kids.

When taking phone messages, helps highlight how to direct scheduling, information transfer, etc. (know to go to care coordinator, etc)

Helps with efficiency and appropriate care, scheduling, resource planning, for registry

When first starting out with practices, look at what they have ongoing, (don't want to completely revamp with new registry) and see what they're missing i.e. might not include date of birth, severity score (1-4 s= social)

**\*\*Dates of birth and diagnosis extremely helpful with transition\*\***

**Ah-ha moment at conference:** Seeing numbers made you realize needed to do more with transition.

We have big access db, can link it back to other things they've said to us.

**Tips**

Registry – Turchi will send template of registry

Implementation guide –

Rural areas, can be 4 hours away from tertiary care center. Don't have computers, use white lined paper. Goal is to see lets see how we can help you/resources - Did a mini-excel workshop.

PA – heterogeneous state with many access issues.

Youth group/parent group – part of medical home concept is family centered care, youth involved in input for care.

Starts slowly, practice identifies one or two parents, bring in Med Home team (care coordinator, etc) and say “we would love it if you would serve in this role of parent partner.”

Might come to staff meetings, parents and youth inspire, resource nights, practice with parent partners, experience in system, parents as spokespeople, parents can teach a great deal about what going on in community

Very simple, quality improvement feedback that practice might not have seen as an issue. Positive feedback and criticism.

Paid parent \$20 money for time, reimburse transportation, etc.  
Fax back referral sheet

Funding from state dept of health – medical home and transition

Number family practitioners going up in conference attending.

Academy of family physicians - Trying to establish medical home in family practice – good relationship with AFP

Had all pediatric practices forward invitation to family practices they transition youth to.

- 1) can bring family practices into the mix
- 2) allow ped practice to sit with family practice
- 3) jointly work on issues

Don't know how many will show up.

Quality improvement –

North Carolina had program linking FP and ped, program now coming to PA and asked them to be a part of it PAFP program

Getting people in the room together

To send: template for transition plan/registry

PA dept health checklist – have modified it and comments why

Send list of tests of change

Improvement on transition numbers – evaluation data (will have in April) – track child longitudinally

What makes successful transition program? Markers of successful transition

Turchi to check with “star” transition program to see if they'll talk to us.

From – St Christopher's hospital for children, from her group that she can recommend

Geographic linking –

Superimpose family practice map with pediatric practice map, and link up practices.

**Healthy & Ready to Work MODELS Project**  
*Interview with Wisconsin program*  
*Interview conducted on February 5, 2008*

**Background**

Not clinical in nature

University Center for Excellence and Developmental Disabilities

Dan director of Center for Excellence – was PI for HRTW demonstration project. Was first time we worked on transition, coincided with six performance measures

We are not direct service state. Model that looked at five or six components – report is on website under “recommendations for states”

Components:

Personalized planning with youth

Community development – building to bring formal and informal support

Interagency cooperative agreement – stakeholder group, decision makers in transition

Continuous improvement

Youth leadership – self determination with youth

Beth was on that staff.

Our CYSHN program divided into five regions. Have state administration, most funds flow into regional centers

Was in HRTW, took over leadership of that project, also coordinates another transition project funded through special education grant.

Took models from original transition project and applied to others

**Sustainability**

\*\* success after funding stops

When HRTW left the state, found other ways to make work continue.

When a new researcher joined, used some elements from the federal transition grant that got funded. With parent educator initiative, help them develop youth council. Continued with statewide transition interagency group. Have continued to bring people in for training for person centered planning.

Have taken the lead for training opportunities in state.

“My goal as a youth educator is to make sure that materials land in the right hands regardless of the program.” Try to be as collaborative as possible (not stuck center by center, my regional center hat on I do this....try not to be divided)

**\*\*collaborations**

Time consuming and challenging. Have to keep asking people to collaborate, offer new incentives. When they see benefit to their own agency, that’s when partnership pays off. DPI – dept of instruction (education) – really challenging. People couldn’t understand

what our goals were, couldn't look beyond our own work scope. Anytime a product came up they could be interested in, emailed them to let them know.

Idea of practice groups, all of a sudden became part of their work plan. Realized that we had a lot of stuff (they had contracted someone for \$40k for something that we already had – realized we were valuable)

**Linkages** – developed transition listserve, grown to 450 people. Takes none of my time, really just forwarding emails. When new initiatives come up, “are you on the transition list serve” – became useful for them. They are useful to us because we get names from them.

Incentives –

Our developed materials seen as useful

DPI wanted to get transition curriculum, were going to contact it out, then realized that HRTW (we) had that already.

\*\*\*Incentive is not paying them, just getting them to see your value and what you bring to table.

### **Barriers**

Barriers to partnerships – every agency operates in different ways, don't have lead person to dedicate “building infrastructure” to.

Had infrastructure grant to facilitate statewide workgroup – now changing to partnership. Interesting to see how will work w/o dedicated person.

Have all families and stakeholders be aware of what we can offer.

Sometimes families think only in terms of health center, need better awareness of regional centers, full range of what they do

### **Workgroup**

Workgroup – “The community on transition”

Rec'd HRTW grant six years ago. Morphed into community practice.

Shared work – can put it all up on website, can share nationally [sharedwork.org](http://sharedwork.org)

Shared work came out of IDEA and education – PA has amazing health materials

Dan has been effective grant writer

Write good grants, and know which grants to go after

When there are grant opportunities, write for them.

Not just funding through grants, but need to help other agencies realize that the work you are doing can help/integrate with their work goals

Youth/parent simultaneous program – have to build capacity of youth same as parents – youth are also calling the shots. Kids need their own space, separate from adults.

Parallel training – same time, different place.

DPI decided their parent educator group would embed some of this into existing grant.

### **Youth**

Besides youth training, youth leadership also huge. Want to create a leadership council. Now their council is presenting at statewide transition conference – facilitating, have own booth, etc.

DPI and our program talking about hiring youth – a part time staff person.

\*\*\* youth leadership very necessary

Need someone early mid twenties. Teens good on advisory committees, panels, etc. But need someone older to do mentoring, systems piece.

### **Community connectors**

In early phases of HRTW, had community building component, but wasn't complete.

**Community connector** – sits down with family for person centered planning, talks through what they need. Not a special Ed teacher, not a job coach, but someone who makes initial introductions. Will be the host and then back out. “I like animals” – connector calls animal shelter, etc. Check in with kids, not just one time thing, build relationship.

Rec'd federal funding for intervention project – intervention that involves person centered planning, also works with community connector.

Become community connector through open application process. Had criteria, publicized by transition listserv.

One is retired teacher, a couple are parents, a couple are just community members who have wanted to get more involved. Might not have kids, but might have connections to school, etc.

Have 7 through HRTW mini-grant (title V)

Have 12-14 through research grant

With infrastructure \$\$, did tertiary care learning collaborative with specialty care centers (UW Madison and UW Milwaukee) went through learning collaborative together. Launched by our regional center w/title V funds. The group continues as a learning collaborative.

MH summit – 100 to 120 participants across the state, annual. Use title V.

Work with specific practices around transition CYSHN. Presentations to doctors in clinics, sometimes staff have face to face visits with them. Talk to them re: effective care for CYSHN. Questions come from practices, what they need help with.

## **Summit**

Early identification  
Community resources  
Transition

Try to have content available at major conferences, all five of regional centers do trainings on the topics (face to face as opposed to listserve) listserve does have an impact, but more for systems oriented families. Health/IEP training. Give out CD rom at resource fairs, talk about it, etc. make sure that all staff are comfortable doing trainings, so they can disseminate.

Have about 100 members who are families.

\*\*\*Always working to expand dissemination of materials to families and providers. A lot of materials developed by HRTW, shared staff working on those, health and IEP, some doctors have helped them, etc.

¼ time with MCHB funded program. Everyone part time except for one person.

## **Evaluation**

A lot of initiatives coming out of multiple programs. Overall evaluation plan?

Regional center GAK objectives – focused on producing outcomes i.e. change in behavior. Have objectives for every initiative – have to fill out surveys after.

Not clinical in nature – more about finding information and resource

Regional I and R centers – information and referral centers.  
A lot of times approach case management, because staff is so good.

Thought that MCH was trying to get away from that ... now hearing about clinical programs.  
Local public health focused on so many things, CYSHN get's lots, parents couldn't access them. (clinical model of before with nurses and medical equipment and only 20 families know about them in the state)

“blessed” with HRTW grant – w/o that, wouldn't have had all the things. Allowed us to go deep within transition. In demonstration project got \$1 mil over four years (\$250k a year)

\*\*\*think we over committed in beginning, if had to do it again, wouldn't have done all publications - would have done three or four as opposed to 8

Would do publications, but taking that much on comes at a cost

### **Future/Tips**

What are ways we can sustain now? If all of us did more of that, would be better. Tendency with grants is to wait until last year of grant to talk about sustainability, and answer is to apply for another grant. – but not what we did.

\*\*\*Need to ask question all the time (even more than we did) – need to convince that their work is your work, and your work is their work – valuable to them.

\*\*\*Don't add on to work you're already doing. If things don't work, replace them. Drop what doesn't work, do things that really matter. Should have done three or four publications that really matter, as opposed to 8.

Tend to think 14-21 yrs for transition.

Helpful links:

<http://www.waisman.wisc.edu/hrtw/Publications.html>

<http://www.waisman.wisc.edu/cshcn/cdrom.htm>