Transitional Care Elective Outline
Russell Kolarik, MD

• Identify key clinical areas that will address health care transition more closely.

• **Common resources**: Adolescent medicine clinic, Cystic Fibrosis Centers, children’s rehab centers, child development programs, Pediatric ICUs, Down syndrome programs, home visits with families of young adults with special health care needs, Med-Peds practices.

• **Special circumstances**: Adult Down Syndrome Clinic, Adult Spina Bifida Clinic, Adult Congenital Heart Programs, Late Effects Oncology clinics, Transitional Care Clinical Programs.

• **Outline educational objectives** for the 2 or 4 week experience.

• Identify educational goals for the resident. Consider content (information) and process (health system) goals and methods of measuring educational impact.

• Suggested educational experiences.

  • **Setting 1**: Home visits
    • **Educational Goals**: Identify specific home-care needs of young adults with chronic medical condition. Identify how their home care needs are impacted by transition to adult centered care.
    • **Learning Method**: Discussions with families, patients and home nurses.
    • **Educational Products**: Complete online health inventory for patient that outlines all home-based health services (therapies, feedings, respiratory needs, nursing care and monitoring, equipment, lab services, and triggers for medical evaluations). **One-paragraph narrative** on continuity of these services when transitioning from pediatric to adult care setting.

  • **Setting 2**: Pediatric Rehabilitation Facility
    • **Educational Goals**: Identify and describe the range of inpatient physical medicine and rehabilitative services available for children
with special health care needs. Identify how those services are impacted with transition to adult care setting.

- **Learning Method**: Conversations with faculty, nursing, therapists, and parents of patients at rehab facility. Residents will learn about outpatient and inpatient physical medicine and rehabilitative services available to young adult patients with special health care needs.

- **Educational Product**: Case write-up of one young adult patient’s physical medicine and rehabilitation needs that are being met at the facility and a plan of action for continuing those services in the adult setting.

- **Setting 3**: Outpatient specialty clinics (Down, Spina bifida, CF, PERC).
  - **Educational Goals**: Identify specific health care needs of a population of children with
  - **Learning Method**: Residents will see patients in clinic and learn from adult specialty providers. Residents will also have conversations with office staff, physicians, patients, and family members. Attention will be given to the medical and health system needs of the specific population. Also, conversations with families and patients in clinic will help identify obstacles to effective health care transition. How did the patient find the adult clinic/provider? Was there a health summary from their pediatrician? How will they find primary care or adult specialty providers? What third-party payer obstacles were in place?

  - **Educational Product**: 1-2 page descriptive narrative of the strengths and limitations of health care transition in one or more clinical settings.

- **Setting 4**: Mentored Independent learning
  - **Educational Goal**:
  - **Learning Method**: Independent reading with selected articles and online modules. Residents will meet once weekly with general medicine faculty who provide transitional care to debrief experiences and review/discuss progress with educational products. Resident will then complete online modules or independent reading on site and discuss with faculty.

  - **Educational Product**: Completion of online modules with pre and post-tests. Also conversation with faculty mentor. Knowledge assessment of care of adults with spina bifida, Down syndrome, pediatric malignancy, cystic fibrosis. Residents may also create their own online module for a scholarly activity with the collaboration of the faculty mentor.
## Transitional Care Rotation
### Proposed month-long elective typical schedule

<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td>AM: Meet with advisor to discuss elective goals, review month schedule</td>
<td>AM: Adult Down Syndrome (DS) clinic</td>
<td>AM: Peds CF clinic</td>
<td>AM: Peds Down Syndrome clinic</td>
<td>AM: adult transitional clinic</td>
</tr>
<tr>
<td>PM: Peds spina bifida clinic</td>
<td>PM: home visit with chronic disease patient</td>
<td>PM: Adult CF clinic</td>
<td>PM: continuity clinic</td>
<td>PM: CMU student health clinic</td>
</tr>
<tr>
<td>AM: Visit Pediatric Rehab facility</td>
<td>AM: Adult DS clinic</td>
<td>AM: Peds Cerebral Palsy (CP) clinic</td>
<td>AM: Pediatric special health care needs clinic</td>
<td>AM: Adult transitional clinic</td>
</tr>
<tr>
<td>PM: Mentored Learning</td>
<td>PM: College student health clinic</td>
<td>PM: Peds sickle cell clinic</td>
<td>PM: continuity clinic</td>
<td>PM: Mentored Learning</td>
</tr>
<tr>
<td>AM: Visit Pediatric skilled nursing facility</td>
<td>All day: Adult Spina Bifida clinic</td>
<td>AM: Peds spasticity clinic (CP)</td>
<td>AM: Peds DS clinic</td>
<td>AM: Adult transitional clinic</td>
</tr>
<tr>
<td>PM: Peds spina bifida clinic</td>
<td>PM: Adult CF clinic</td>
<td>PM: Adult CF clinic</td>
<td>PM: continuity clinic</td>
<td>PM: College student health clinic</td>
</tr>
<tr>
<td>AM: Mentored Learning</td>
<td>AM: Adult DS clinic</td>
<td>AM: Peds CF clinic</td>
<td>AM: Pediatric special health care needs clinic</td>
<td>AM: Adult transitional clinic</td>
</tr>
<tr>
<td>PM: Peds spina bifida clinic</td>
<td>PM: College student health clinic</td>
<td>PM: Adult CF clinic</td>
<td>PM: continuity clinic</td>
<td>PM: Meet with mentor for rotation wrap-up. Fill out evaluation and survey.</td>
</tr>
<tr>
<td>PM: Mentored Learning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Teaching Childhood-Onset Chronic Medical Conditions: Outline for Developing an Educational Tool

Mary E. Brown, MD

- **Identify topics of educational need:** Which childhood-onset chronic medical conditions do transitioning adolescents have most commonly? Which conditions are internists seeing most often in practice? Which conditions are they most uncomfortable caring for? Which conditions have the most adult health care implications?

- **Develop specific learning objectives:** Should focus on practical generalist concerns or other identified needs related to the childhood-onset chronic medical conditions. (eg. common adult manifestations of the condition, additional or different health maintenance guidelines, guidelines for screening for associated disorders, etc.).

- **Identify key resources for content:** Includes texts, current literature review, practice guidelines, policy statements, local experts in the field. Consider that the experts might be in pediatrics.

- **Select an educational method:** In order to increase learner buy-in and ease, consider using pre-existing venue, such as existing web-modules, other self-study systems, adolescent medicine lecture series, pre-clinic conferences.

- **Develop the educational materials:** This may be time-consuming. Consider collaboration with interested faculty (in medicine and pediatrics) or content experts to minimize the self-learning burden for the developer. Review content of materials with available experts. Consider having medical editor review materials for style and consistency.

- **Implement the educational materials:** use expert resources available to maximize ease of implementation by identifying how the educational materials may fit into existing curriculum structure – such as existing web-based education, noon conferences, pre-clinic conferences, other self-study education, PBLs.
• **Evaluation of the educational materials:** Development often follows development of learning objectives. Usually pre-/post-test questions to assess knowledge. Find guidelines for writing test questions on the NBME website: [http://www.nbme.org/publications/item-writing-manual-download.html](http://www.nbme.org/publications/item-writing-manual-download.html). Also consider pre-/post-evaluation of attitudes – if educational tool is part of larger series related to childhood-onset chronic medical conditions, adolescent medicine, or transitional care. May also measure attitude with a stand-alone educational tool.

---

**EXAMPLE:** Development of curriculum addressing childhood-onset chronic medical conditions in adolescents and adults for internal medicine residents at the University of Pittsburgh

1) Educational needs assessment of GIM faculty identified Down Syndrome as a topic of educational need.

2) Learning objectives for a curriculum about Down Syndrome in adults was developed:

**EXAMPLE:**
- List the major causes of mortality in adult patients with Down Syndrome.
- Discuss ways to minimize the risk for the major causes of mortality in patients with Down syndrome.
- Identify signs and symptoms of disorders that are commonly associated with Down syndrome.
- Describe the recommended schedule for surveillance of disorders that are commonly associated with Down Syndrome.
- Identify symptoms of comorbid mood or behavior disorders in patients with Down Syndrome

3) Developed knowledge-based multiple choice test questions based on learning objectives to be used as pre-/post-test questions in the evaluation of the curriculum. Also developed an attitudes survey to be given prior to the implementation of the curriculum and after 4 months of implementation of the curriculum in order to evaluate change in attitudes.

4) Performed literature search on topics related to learning objectives. Identified policy statements and practice guidelines about Down Syndrome in adults. Consulted with director of adult Down Syndrome clinic for expert opinion about content and resources.

5) Chose to develop curriculum as an educational module in the adolescent medicine curriculum for a pre-existing web-based pre-clinic module system which the residency was currently using.
6) Developed an outline for module content and then developed the web-based module

EXAMPLE:

- **INTRODUCTION**
  i. Approach to the management of Down syndrome
  ii. Instructions for this module
- **PRE-TEST**
- **OVERVIEW**
  i. Etiology and epidemiology
  ii. Challenges of health care
- **ENT, CARDIAC, AND PULMONARY CONDITIONS**
  i. Quiz 1
  ii. Obstructive sleep apnea
  iii. Hearing loss
  iv. Congenital heart disease
  v. Valvular heart disease
  vi. Pneumonia, aspiration, and influenza
- **GASTROINTESTINAL AND ENDOCRINE CONDITIONS**
  i. Quiz 2
  ii. Celiac disease
  iii. Thyroid disorders
  iv. Diabetes mellitus
- **MUSCULOSKELETAL CONDITIONS**
  i. Quiz 3
  ii. General orthopedic problems
  iii. Atlantoaxial instability
- **NEUROLOGIC, PSYCHIATRIC, AND BEHAVIORAL CONDITIONS**
  i. Mental retardation and development
  ii. Seizures
  iii. Alzheimer's disease
  iv. Attention-deficit/hyperactivity disorder
  v. Quiz 4
  vi. Obsessive-compulsive disorder and anxiety
  vii. Depression
- **CANCER**
  i. Malignant disorders
- **REPRODUCTIVE HEALTH CARE**
  i. Sexual education
  ii. Quiz 5
  iii. Screening and counseling for women
  iv. Screening and counseling for men
- **PSYCHOSOCIAL CONSIDERATIONS**
  i. Consent
  ii. Estate planning and transition planning
- **SUMMARY AND REFERENCES**
- **SURVEY AND POST-TEST**
7) After completion of the module development, again consulted the director of the adult Down Syndrome clinic as a content expert to review the content of the module as well as the pre-/post-test questions. Additionally, a medical editor in the division also reviewed the module for style and consistency.

8) Prior to making the web modules available on the pre-clinic module site, the residents were asked to complete the pre-curriculum attitudes survey.

9) The web modules were made available to the residents on the pre-existing and well known pre-clinic module website. Pre-/post-test questions were embedded as part of the module.

10) After the Down Syndrome web module have been available for 4 months, they will be made temporarily unavailable while the residents are again asked to complete an post-curriculum attitudes survey.
Educational Goals for Residents Caring for Adolescents with Special Health Care Needs Transitioning to Adult-Oriented Health Care

**Goals for subsession:**
To outline learning objectives and goals for residents
- rotating through a transitional clinic
- working with physicians who see adolescents with special health care needs
- who are caring for adolescent with special health care needs in their continuity clinics

**Case:** BG is an 18 year old woman with a PMH significant for mental retardation, minimal verbal skills, and epilepsy, who is scheduled to see you to establish care as a new patient. She is accompanied by her mother who provides the history; none of her medical records are available. She is transitioning from pediatric primary care per the request of her parents.

She had previously been doing well until about one month prior when she came home from school not acting like herself (less active, less engaged with her surroundings and family). She subsequently developed vocal and motor tics. She was hospitalized at the Children’s Hospital shortly thereafter and there no findings of active seizures or infection. Her physicians believe her symptoms are primarily behavioral, however her parents are not sure. BG had previously been on risperidone and citalopram for skin picking, which have been discontinued. Her mother wonders if she could be having extrapyramidal side effects from these medications, migraines, or if it could be related to her menstruation as symptoms began about 1 week prior to a period.

On exam her vitals are normal, she has short stature and dysmorphic features. Minimally interacts with you during exam. Her exam is otherwise unremarkable.
Questions to stimulate discussion and reflecting educational goals for residents:

1. What is transition?
   
   a. When should it happen?
      i. At what age?
      ii. What kind of preparations should be made?

   b. Who should lead the transition process? AND Who should be part of the transition “team”?

   c. What are barriers to transition and potential solutions to those barriers?

2. Sources of patients: Referral/recruitment opportunities

3. How are the patients transitioned – how were the handoffs operationalized?

4. How does one know what a specific patient’s needs are?

5. How does one find services in the adult world?

6. How does one manage the insurance coverage issues?
Educational Goals for Residents Caring for Adolescents with Special Health Care Needs Transitioning to Adult-Oriented Health Care
Alda Maria Gonzaga, MD, MS

1. What is transition?
   a) The process of shifting from child-centered to adult-oriented lifestyle/activities – in this case, medical care
   b) When should it happen?
      i. At what age?
         1. Depends on the patient –
            a. Ideal:
               i. Whenever they are ready
               ii. Should not be concurrent with any medical crises
            b. In reality:
               i. by age 21 years for inpatient care
               ii. whatever age their pediatrician stops seeing patients (between 18-21y)
      2. If patient is cognitively intact –
         a. When the patient is able to describe the signs and symptoms that require urgent medical treatment.*
         b. When the patient understands the implications of their condition and treatments on their life in general, particularly their sexuality and reproductive health.*

* These are the 2 conditions physicians ranked most important in successfully transitioning patients to adult-oriented healthcare.

ii. What kind of preparations should be made?
   1. The process should begin early with planning for the future – education for patients, providers, and families about the importance of developmentally appropriate and coordinated transition
   2. Can be envisioned as 3 stages:
      a. “Envisioning a future” – begin discussing transition to adulthood (what the reality of that will be like) as soon as condition is identified
      b. “Age of responsibility” – time when family members begin to allow the child/adolescent to take on more responsibility in their day-to-day lives (e.g., speaking to their physician about their condition, being responsible for ordering and taking their medications) – for cognitively intact patients, this may even begin before the onset of adolescence
      c. “Age of transition” – transitioned to adult-oriented health care and begins to live more independently (ideally)
   3. Identification of providers to care for patient in future: internist or family physician, subspecialists – so that pediatrician can given name of a single provider to patient and family (for PCP, for subspecialty, etc).
   4. Communication with providers regarding patient
      a. Transition note
         i. a concise and relevant medical summary
ii. current problem list
iii. current medical subspecialists involved in the patient’s care
iv. medication list
v. immunization history
vi. strategies for working with and using the medical expertise of the patient and his/her family

b. Why is communication important?
   i. To allow provider time to learn patient’s medical history prior to initial visit
   ii. To determine how long to make the initial appointment for the patient (if accepting provider as flexibility)
   iii. To make specific accommodations for the patient, e.g. ASL interpreter, if necessary
   iv. (Patient selection in a new program)

c. Consider a transition visit with both the pediatric and adult providers/“transition clinic”
   i. Advantages:
      1. Improves patient satisfaction and lessens anxiety
   ii. Disadvantages:
      1. Only one of the 2 providers gets paid
      2. Transition clinics – patients initially seen by both providers, then by adult caregiver at pediatric site, and ultimately by the adult provider at the adult-care site → funding is major issue

c) Who should lead the transition process? AND Who should be part of transition team?
   i. Who should lead the transition process?
      1. Make sure there is a single health care professional responsible for the process
      2. Should this person be the PCP or someone else?
         a. Depends on the patient
         b. Some patients are transitioned beautifully when a nurse practitioner who knows them well coordinates the process
         c. For others, the PCP would like to coordinate it
         d. For patients with specific chronic health concerns (CF, sickle cell) it is often the subspecialist who coordinates transition
   ii. Who should be part of transition “team,” i.e., be involved in transition process?
      1. Patient and family
      2. PCP/provider who know patient best (e.g., physician extender)
      3. subspecialists
      4. providers who will care for patient in future (PCP and subspecialists)
      5. social worker – may be helpful in addressing concern about health care financing once patient becomes an adult
d) **What are barriers to transition and potential solutions to those barriers?**

i. **Barriers:**
   1. Lack of adult oriented physicians who understand or are willing to take care of patients with special needs (Adults providers concerns about providing care to patients with conditions they may not be familiar treating)
   2. Pediatricians’ apprehensions regarding the care their former patients may receive in an adult care setting
   3. Parental lack of willingness to transition (fear and ambivalence)
   4. Patient lack of willingness to transitions (fear and ambivalence)
   5. Not starting/talking about transition process early
      a. more common in patients with more serious conditions
      b. even if they talked about it, may not have a formal plan to transition
   6. Interruption in health insurance coverage
   7. Lack of an accessible model for transition
      a. Most common transition programs are:
         i. general adolescent health models – providing a wide range of services for adolescents with chronic conditions
         ii. disease-specific models – focusing on one specific disease (e.g., CF or sickle cell)
   8. Lack of institutional support for transition programs/lack of funding
      a. Transition patients usually take more time in the office (and therefore may not be reimbursed adequately) and between office visits for form completion (which is not reimbursable)
      b. Can lead to provider fatigue – feel they cannot care for more than 10-12 patients in a general medicine practice due to amount of time spent in care coordination

ii. **Potential solutions: What we have in place at UPMC = Progressive Evaluation and Referral Center (PERC)**
   1. Physicians trained in combined internal medicine-pediatrics who are knowledgeable and willing to care for patients with complex medical issues
   2. A network of collaboration with specialists in the UPMC system and the Children’s Hospital of Pittsburgh
   3. Willing to meet patients in pediatricians’ office or during a hospital stay if that will help the transition process and if scheduling permits (on limited basis and if time permits)
   4. An inpatient service, so that in the event a patient is admitted a member of our practice will care for him/her (admitted to our hospitalist service)
   5. **Institutional support**
      a. Longer patient visits (1½ hour for an initial visit, 45-60 min for follow-up)
   6. A facility that is disabilities friendly

2. **Sources of patients: Referral/recruitment opportunities**
   a) A letter explaining clinical interest/clinical program to pediatricians who care for patients with special health care needs
At UPMC this began with the Diagnostic Referral Service at Children’s and spread by work of mouth to private practice pediatricians

b) Networking with subspecialists
   i. Medical geneticists
   ii. Diagnostic referral pediatricians
   iii. Pediatric physiatrists
   iv. Pediatric intensivists
   v. Subspecialists
      1. heme/onc for sickle cell patients or childhood cancer survivors
      2. pulmonary for CF
      3. neurology for muscular dystrophy

c) Patient word of mouth

3. How are patients transitioned – how were handoffs operationalized?
   a) See preparations for transition above
   b) UPMC experience:
      i. Most had transition note or transition phone conversation prior to initial office visit.
         1. Allowed for familiarization with medical history
         2. Allowed for familiarization with medical problem (e.g., specific genetic syndrome and practice guidelines available for it)
         3. Confirmation of history during visit was brief
         4. Allowed opportunities to flesh out functional status, social history, long-term goals, estate planning, etc.
      ii. BG only patient who showed up unannounced
         1. Take home points:
            a. Stay calm
            b. Cover only what is necessary during initial visit
            c. Be supportive of family/validate their concerns while voicing limits (lack of past records, expertise, etc).
            d. Order any testing you feel is appropriate
            e. Have patient/parent sign medical release form for previous medical records from pediatrician, subspecialists, and hospital stays
            f. See patient back soon

4. How does one know what a specific patient’s needs are?
   a) Willingness to educate oneself
      i. Read about patient’s conditions
      ii. Talk to subspecialists (e.g., medical geneticists, subspecialists)
         1. They may know about good online texts
            a. Down Syndrome has health maintenance guidelines available online
         2. They may have good website to support providers
            a. Cornelia De Lange Syndrome has a great website
      iii. Use your patient and their family as your experts
         1. Mother of a patient with Lesch-Nyhan gave me a great New Yorker article describing the experiencing of having Lesch-Nyhan
5. **How does one find services in the adult world?**
   a) Requires investigation and networking with other providers (especially PM&R and social work)
   b) Learn from your patients and their families regarding their experiences
   c) Talk to subspecialty colleagues
   d) Local county boards of the Mentally Retarded and Developmentally Disabled can help identify allied health care providers with training or experience in caring for individuals with disabilities.
   e) Work with a social worker or social service agencies!
      i. The Pittsburgh area has social services agencies (e.g., FamilyLinks) that provide case management, in-home and community support coordination (e.g., for enrollment in vocational programs) for people with mental retardation
      ii. Other social services agencies (e.g., Glade Run Lutheran Services) provide similar services for people with mental illness

6. **How does one manage the insurance coverage issues?**
   a) Work with a social worker or a social service agency!
   b) Someone knowledgeable about legal rights should review entitlements with patient and family (including eligibility for Medicaid and/or Social Security Income)
   c) Social Security Disability Income
      i. Eligible for patients who became disabled prior to age 22 years if at least one of their parents worked under social security and is now disabled, retired, and/or deceased (but often leads to loss of SSI and Medicaid eligibility; eligible for Medicare after 24 months)
   d) See White article in Pediatrics (2002) for more details

**References**
The Adult Down Syndrome Center  
Peter Bulova, MD

Educational Goals for Residents Caring for Adults with Down Syndrome

**Goals for sub session:**
To outline learning objectives and goals for residents
- Describe the unique medical issues of Adults with Down Syndrome
- Demonstrate understanding of the complexity and need for comprehensive care of patients in special needs populations
- Understand the issues surrounding transfer of care from pediatric to adult care in people with Down Syndrome

**Case:** ML is an 18 year old woman with a PMH significant for Down Syndrome with mild mental retardation. She is scheduled to see you to establish care as a new patient. She has been having difficulty leaving her home due to daily diarrhea and has subsequently developed anxiety when leaving her house. She is often tired and takes naps every afternoon. Her family had been told, “that is just the Down syndrome.”

**Questions to stimulate discussion and reflecting educational goals for residents:**

7. What are the unique medical issues in Down syndrome and when do they present?  
8. How does one approach a patient with Down Syndrome changing to an Adult provider?  
9. What special needs are there for patients with Down Syndrome?  
10. What are barriers to transition and potential solutions to those barriers in patients with Down Syndrome?
Sheet #2: 13 Years to Adulthood

Name: ________________________________         Birthday: ______________________________

<table>
<thead>
<tr>
<th>Age, in years</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
<th>18</th>
<th>19</th>
<th>20-29</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usual Preventative Care</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Audiologic Evaluation</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Ophthalmologic Evaluation</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Thyroid (TSH &amp; T₄)</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Nutrition</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Dental Exam¹</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Parent Support</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Developmental &amp; Educational Services</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Neck X-rays &amp; Neurological Exam²</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Pelvic exam³</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
<tr>
<td>Assess Contraceptive Need³</td>
<td>___</td>
<td></td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td></td>
</tr>
</tbody>
</table>

Instructions: Perform indicated exam/screening and record date in blank spaces. The shaded boxes mean no action is to be taken for those ages.

¹Begin Dental Exams at 2 years of age, and continue every 6 month thereafter.
²Cervical spine x-rays: flexion, neutral and extension, between 3-5 years of age. Repeat as needed for Special Olympics participation. Neurological examination at each visit.
³If sexually active.

© Down Syndrome Quarterly, 1999. This record sheet may be printed out for individual use but may not be reproduced on any website without prior permission.
Medical Issues in Patients with Down Syndrome

- **Cardiac:**
  - Congenital Cardiac Abnormalities 50%

- **ENT:** Small Mid Face
  - Sleep Apnea 30-50%
  - Decreased hearing 25-70%
  - Sinusitis
  - Cerumen impaction

- **Endocrine**
  - Hypothyroidism 13-63%
  - Hyperthyroidism 5-10%
  - Diabetes

- **GI**
  - Celiac Disease (Wheat allergy): 10-20%
  - Difficulty swallowing: 30-50%
  - Reflux

- **Psychiatric** 40%
  - Anxiety
  - Depression
  - OCD
  - ADD
  - Psychosis

- **Neurologic**
  - Dementia
  - Seizures

Guidelines for care:

1. **Cancer Screening:**
   - Annual testicular exam
   - Discussion regarding pap smear and mammogram frequency based on risk factors (sexually active, age of onset of intercourse, number of sexual partners, history of HPV infection, cigarette use)
   - No routine screening for prostate cancer
     - Annual TSH/ T4
     - Vigilance for Osteoporosis
     - Ophthalmologic exam every 2 years
     - Audiogram every 2 years
     - Dental
       - Recommend evaluation every 6 months
       - May require more frequent care if dental disease
         - Cavities tend to be less common
         - Gum disease tends to be more common

2. **Comprehensive approach to healthcare**
- Audiology
- Vision
- Speech Therapy
- Physical Therapy
- Dental
- ENT
- Psychiatry
- Pulmonary
- GI
- Cardiology

**Transition to Adult Life**

- Recreation/Leisure Activities
  - Identify activity interests
  - Community connections
- Job Training/Acquisition
  - Volunteer opportunities
  - Community connections

Impact on Employment Goals:

- Limited strength and stamina
  - Musculoskeletal challenges
    - Flat, pronated feet
    - Atlanto-axial instability
    - Joint laxity (knees/hips)
  - Thyroid dysfunction
  - Sleep apnea
  - Chronic infections
    - Seasonal allergies?
    - Environmental factors

- Language impairments
  - Hearing
    - Limitations
      - Environmental
      - Medical causes
      - Sensitivities
  - Expressive Language
    - Limited verbal skills
    - Articulation/dysfluency

- Nutritional concerns
  - Celiac disease
  - Gluten free diet
  - Food Allergies

- Weight management issues
- Visual Impairments
  - Congenital cataracts
Topics for Transition planning:

- Memory
- Sensory
  - Hearing, vision, touch, taste, pain
- Communication
  - Expressive and augmentative
- Health related topics
  - Weight Management
- Psycho-social concerns

References:

- *Trisomy 21 – Down Syndrome Growing up – Transition to Adult Life*: Sheila Cannon, M.Ed
- *Down Syndrome: Care of the Child and Family*: William I Cohen, MD
- *Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges*: Dennis McGuire, Ph.D., Brian Chicoine, MD.