Transition at General Hospital Vienna/ Medical University Vienna

Past, presence and future within EUHA

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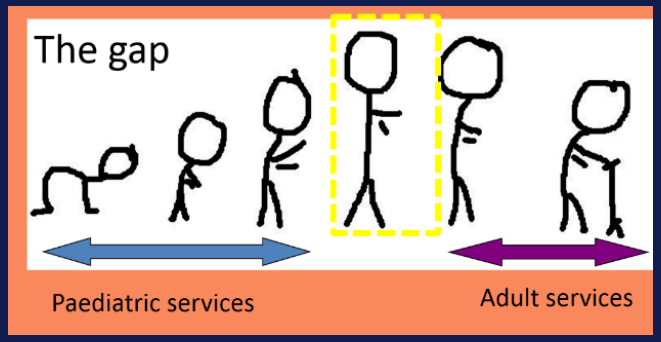
PAST

>20 years pediatric specialties established „self constructed“ ways to transist young adult patients with chronic diseases to adult care, for example chronic heart diseases to cardiology, cystic fibrosis to pulmonology …. and others stayed at the pediatric department.



Realizing and defining „the gap“

PROGRESS

Starting research projects / publications on the topic of transition

Clinicians, psychologists, national and international societies increasingly start initiatives for standardized transition

Conclusion (example Turner Syndrome*):

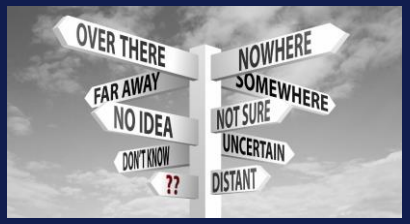
- Medical follow-up was inadequate
- Patients felt inadequately treated and leaving them vulnerable for longterm health risks.

urgently needed:

- structured transfer process and initiatives improving health autonomy
- closer collaborations within specialities

*Ertl DA, Gleiss A, Schubert K, Culen C, Hauck P, Ott J, Gessl A, Haeusler G. Endocr Connect. 2018 Apr;7(4):534-543. doi: 10.1530/EC-18-0053. Epub 2018 Mar 7. PMID: 29514898

Barriers of successful transition



Example 1 Inborn Disorders of metabolism IMDs

Special requirements

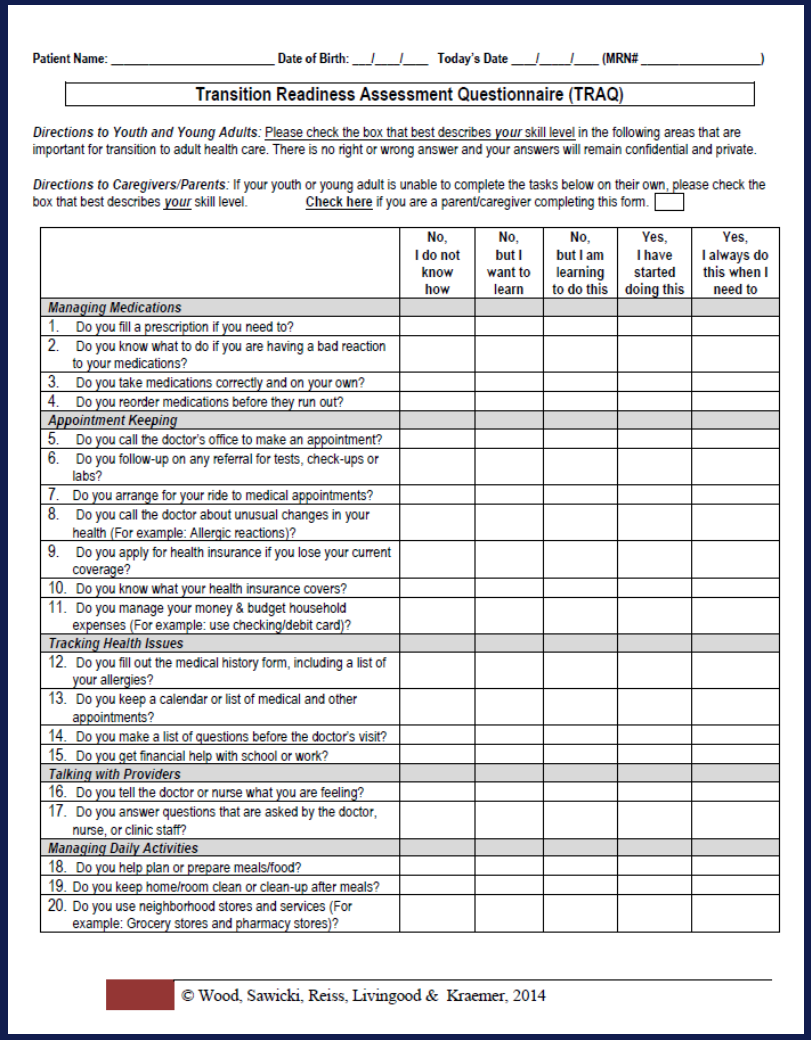
Common barriers

Challenges in transition for IMD patients Multisystemic nature of IMDs – need to be followed by multiple professionals

- Developmental delays/intellectual disabilities must be taken into consideration
- Dietary care is often complex; IMD's emergency protocols should be made available for facilities specialised in adult care
- shortage of physicians specialized in the adult care of IMDs
- lack of standardized programs or specific guidelines shared across Europe
- lack of financial resources

ORIGINAL RESEARCH article
Front. Med., 25 February 2021 | https://doi.org/10.3389/fmed.2021.652358

Transition Readiness Assessment Questionnaire



Patient Name: _____ Date of Birth: ___/___/___ Today's Date ___/___/___ (MRN#_____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes *your* skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes *your* skill level. Check here if you are a parent/caregiver completing this form. ☐

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

All cross-culturally adapted TRAQ questionnaires share the features of easy administration, good comprehensiveness and applicability for all chronic conditions (Anelli et al., 2018; Gonzalez et al., 2017; Kızıler, Yıldız, & Eren Fidancı, 2019).

questionnaire designed to assess self-management and self-advocacy
TRAQ 5.0, Wood et al 2014

Further initiatives to improve transition at the Dep. Pediatrics and Adolescent Medicine, Vienna

- **Workshops** for adolescents to improve disease-related knowledge and skills in same clinical specialities (ongoing)
- **SOPs** to define the responsibilities of clinical psychologists in the transition process at our department (in prep.)

- Enhancement of autonomy and self-care through **medical and psychological counselling**.

Adolescent medicine

Table 2. Provider transition checklist and timeline

Transition step	Ages 11–13	Ages 14–16	Ages 17–19	Ages 20–22
Transition preparation				
Encourage the adolescent to assume increasing responsibility for his/her healthcare management	❑	❑	❑	❑
Meet privately with the adolescent for part of the visit	❑	❑	❑	❑
Assure the adolescent understands his/her health condition and medications	❑	❑	❑	❑
Assess the adolescent's and the family's readiness for transfer to an adult care provider[a]		❑	❑	❑
Address gaps in preparation, knowledge and skills[a]		❑	❑	❑
Transition planning				
Address healthcare transition needs		❑	❑	❑
Assess the need for guardianship/conservatorship; assess the adolescent's ability to make independent decisions		❑	❑	❑
Create Healthcare Transition Action Plans, Portable Medical Summary		❑	❑	❑
Identify possible adult care providers			❑	❑
Initiate communication with the adult provider			❑	❑
Transition and transfer of care:				
Send 'Transition Package' and transfer letter			❑	❑
Discuss nuances of care with the adult provider via direct communication			❑	❑
Follow-up after the transfer			❑	❑

Lemly et al Curr Opin Pediatr 2013

Future

Collaboration with EUHA

Set of minimal requirements for managing transition

Joint research projects