Optimizing the Care of Young Adults with Intellectual Disabilities through Adulthood

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Definition

- Intellectual disability is a below-average cognitive ability with 3 characteristics:
  - Intelligent quotient (or I.Q.) is between 70-75 or below
  - Significant limitations in adaptive behaviors (the ability to adapt and carry on everyday life activities such as self-care, socializing, communicating, etc.)
  - The onset of the disability occurs before age 18
Significance

Young Adults with Intellectual Disabilities and their Caregivers

Pediatric Healthcare System

Adult Healthcare System
Background

- Children with Intellectual and Developmental Disabilities grow up to become adults with Intellectual and Developmental Disabilities

- Adult healthcare systems are not equipped to provide comprehensive care for young adults with IDD

- It is important to identify key risk factors that lead to adverse health outcomes for young adults with IDD

- There may be some similarities in the way care is delivered for adults young adults with IDD and older adults with Dementia
Aims

- Identify similarities and differences in care between young adults with IDD and elderly adults with Dementia

- Describe barriers and facilitators of care for adults with intellectual disabilities as perceived by adult primary care providers
Methods

- In order to identify the similarities and differences in care of young adults with IDD and older adults with Dementia, we needed to gather perspectives from adult care providers.

- Providers were asked to participate in an in-depth phone interview.
Study Design

- **Qualitative Study involving in-depth phone interviews**
  - Secondary analysis of larger study

- **Study Population:** Twenty-one adult medical providers were selected based on their known practice of providing care for young adults with pediatric chronic conditions (including IDD)

- **Recruitment:** Snowball Methodology

- **Phone Interviews were electronically recorded then transcribed**

- **Interviews were coded using QSR Nvivo 10**
Interview Guide

- Providers were asked in depth questions about the care of adults with pediatric chronic conditions (including IDD)

- We asked about:
  - The Transfer Process
  - Similarities and differences between the young adult and elderly adult population with chronic disease
  - Similarities and differences between young adults with IDD and elderly adults with Dementia
  - Training Needs and preferences
  - Billing needs
Analysis

- Similarities in Care
- Differences in Care
- Wish List
- IDD Currently Helpful
Analysis

♦ Similarities in Care

- Medical Supports: institution/residential placement, follow-up care, social work, time needed for visits, trouble with instructions, need for home-based care, assessing depression
- Non-Medical Support: transportation
- Family Involvement: family dependence
- Safety: need for safety screening, wandering, falls, home safety
- Patient Population: vulnerability
- Insurance
Analysis

• **Differences in Care**

  - Medical Supports: young adults required more time, young adults required more forms, staff/physician discomfort with young adults, equipment, less availability for cognitive testing for young adults, young adults had challenging behavior, young adults faced transition of care
  - Non-Medical Supports: taking away privileges for elder adults, young adults required more vocational supports
  - Insurance: Medicaid v. Medicare, lack of coverage for young adults
  - Patient Population: severity of condition
  - Safety
  - Family Involvement
Similarities in Care

- Safety
  - Concerns for safety

“Yeah, I mean you have to provide the appropriate amount – you have to provide a safe environment for the person. You have to be able to assist them, going to the bathroom and care for wounds and all, if the person is really bed-bound. And again, it’s frequently much easier with children that get transitioned, because usually you have two parents, for the most part that will participate in the care in addition to usually a caregiver, depending on what the insurance is available.” –Provider 1

“I think that, you know, they’re – the similarities are, you know, that you can have a lot of the same safety problems with wandering behaviors with people getting lost with, you know, safety things around the house. So I think a lot of those you can use, you know, similar sorts of counseling, similar sorts of supervision that might be required, but I think there’s a lot of differences too. Yea, I think the big similarities would be the similar kind of safety concerns and need for supervision.” –Provider 2
Non Medical Supports

- Transportation

“You know, we do have a lot of patients who don’t want to come back because they – they’re having – they really do have – or we have a problem with transportation too because of a lot of our patients don’t drive. And we can get free transportation for them through medical access too but they don’t always know about that so I think a lot of them aren’t – they don’t know about the resources that are available and we probably don’t do a good enough – that’s one of the things we should probably doing – be doing at our initial counseling too, is letting them know about the programs that are out there to help with that kind of problems.” –Provider 3

“We had some transportation issues at some visits related to the patient showing up on time.” –Provider 4
Differences in Care

- **Medical Supports**
  - More intensive care and follow up

  “…for a lot of these young adults especially the ones with the very high special needs, is that it takes a lot more. They’re it just takes a lot more of everything, the time for, you know, lots of phone calls, a lot of prior authorizations for medicines, I have letters of medical necessities or like just at least once a month and, you know, nursing, the equipment for home…” –Provider 1

  “I have probably, you know, maybe five – currently five or six young adults who fall into this category of the one with developmental disability and, you know, just very high needs in terms of feeding devices and medical things like that.” –Provider 2
• The Transition

“I always worry that I’m referring to the wrong place where their appropriate specialists are not available and then across the board these complex patients almost always go to the PICU so then they’re there for a while, which is not a challenge at all because of how great the care is there and then how great the communication is back and forth keeping me in the loop so – but yea, those are – that’s a big challenge and, and there’s a little bit of guilt on my part that I feel when one of these patients who has been transitioned still ends up being admitted at CHOP because I feel like that’s sort of a failure of transition and that’s something that obviously, you know, I mean I myself have to work through but also as a system, you know, that’s something that needs to be addressed as well but it’s hard when they have specialists all over the place” –Provider 3

“I mean you have to spend time with a young adult patient explaining how this is different from when they saw their pediatrician whereas you don’t have to do that with an older adult patient. Usually older adult patients have some experience navigating the medical system on their own which the young adult patients usually do not.” –Provider 4
• Lack of resources

“the difference is that the resources are different in adults with dementia. We have a very good geriatric center that provides support for adults that have dementia and we don’t have those resources for our younger patients with special needs.” —Provider 5

“The department of aging I think has more supports for people throughout with dementia and it’s different resources.” —Provider 6
Differences in Care (Cont.)

❖ Insurance
  • Lack of Coverage

“I think that’s one of our big challenges and I think the other issue is that, you know, we still do have a lot of patients who have problems with having insurance coverage and prescription coverage. That is a huge issue for the young adults especially when they’re not in school. And, you know, we do – I think sometimes just telling – you know trying to get them to understand that I don’t care if they don’t have coverage, they can, you know, I’ll see them, we’ll figure something out.” –Provider 7

“There are a few insurances that our practice doesn’t cover and it does make it very difficult to care for a patient because they really can’t come – the bills are pretty high; they can’t come to our clinic if their not accepted.” –Provider 8

“I mean obviously if we had, you know, more universal coverage for young adults and – with preexisting conditions, were gone that would help tremendously, because I do still see a lot of patients who loose coverage or can’t afford coverage because of the diagnosis of epilepsy. So that is still a problem for our patients.” –Provider 9
Differences in Care (Cont.)

- Family Involvement
  - Guardianship

“And I talk to them also – I try to, but I don't always get to this – is kind of estate planning. What are the parents going to do if their patient – if their son or daughter with cognitive impairment has – outlives them? Where are they going to go? What are they going to do? Have they talked about living wills, power of attorneys? Who's the guardian? Have they talked about getting any kind of – putting the patient into any group home? Has that been an issue that they've had to talk about?” –Provider 10

“And then there are the young adult patients who have cognitive disabilities and actually have guardianship issues and those patients tend to be able to show up but they're reliant on their parents or guardians to bring them.” –Provider 11

“Well I had one a couple of weeks ago where the patient lived in a group home and the group home staff and his family were there and they were not on the same page with regard to his diet and it got a little heated in the room and that was – that was not fun. So when everyone's not on the same page. That can be a challenge.” –Provider 12
Conclusions

Establish a *team*

Determine the family/guardianship situation and define their role in care

Create a **transition care plan**

Maximize resources

Create a **comprehensive care plan**
What I’ve Learned…

- Qualitative Research Methods
- The Importance of both Patient and Provider perspectives
- The Importance of TEAMWORK
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Questions?

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