

Gatekeeping, intellectual disability (ID), and access to transplant

Aaron Wightman MD MA



Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

Bioethics and Palliative Care



UNIVERSITY of
WASHINGTON

A Book and a Case

Gatekeeping

- “Goal is to optimize the **patient’s** chances for survival and to offer him as enduring, active, and meaningful a post transplant life as possible without undue physical, psychic, or social harm to himself, the donor, or their families.” p.7

Amelia Rivera

Fox ReC, Swazey JP. *The courage to fail : a social view of organ transplants and dialysis*. 1974

Attitudes and Beliefs 1990

- Survey of 411 transplant centers (adult and peds)

	Heart (%)	Liver (%)	Kidney (%)
IQ <70			
Absolute	26	11	3
Relative	59	70	51
Irrelevant	15	19	46
IQ<50			
Absolute	75	46	24
Relative	19	41	52
Irrelevant	6	13	24

Olbrisch ME Levenson JL. *J Heart Lung Transplant* 1991
Levenson JL, Olbrisch ME. *Psychosomatics* 1992

Attitudes and Beliefs 2020

	Wall et al. 2020	Levenson & Olbrisch 1990		
	Heart/Liver/Kidney	Heart	Liver	Kidney
IQ <70				
Absolute	1	26	11	3
Relative	64	59	70	51
Irrelevant	35	15	19	46
IQ<35		IQ<50		
Absolute	25	75	46	24
Relative	59	19	41	52
Irrelevant	16	6	13	24

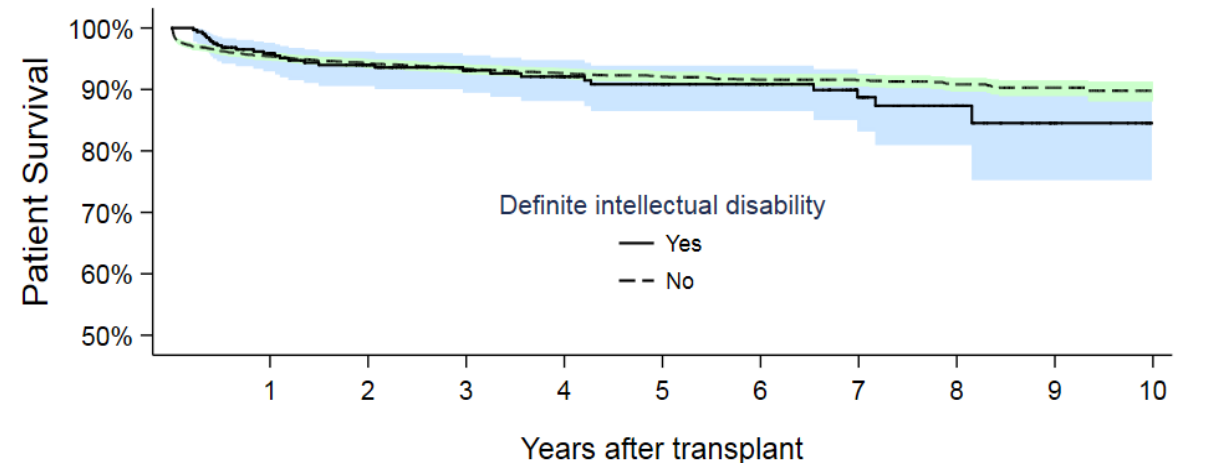
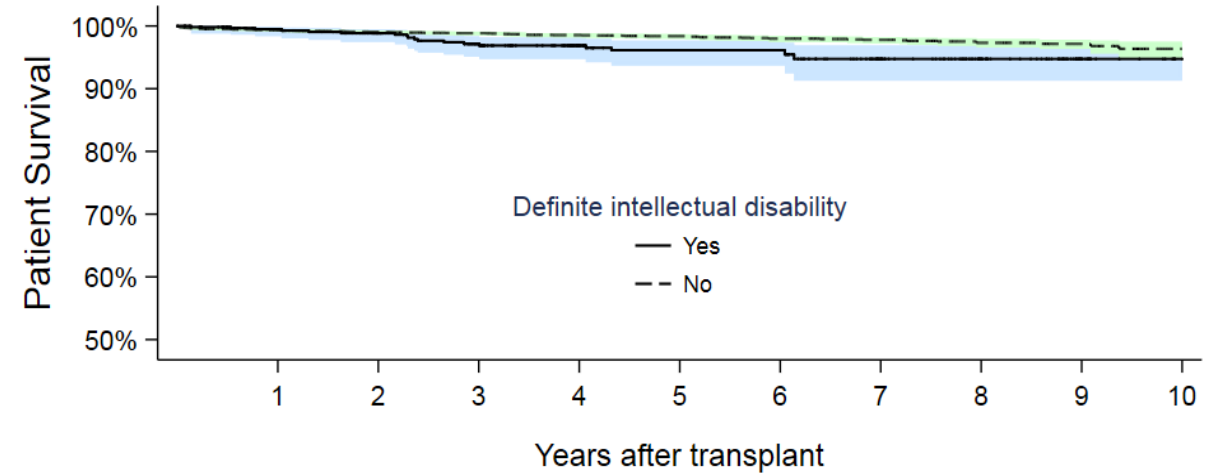
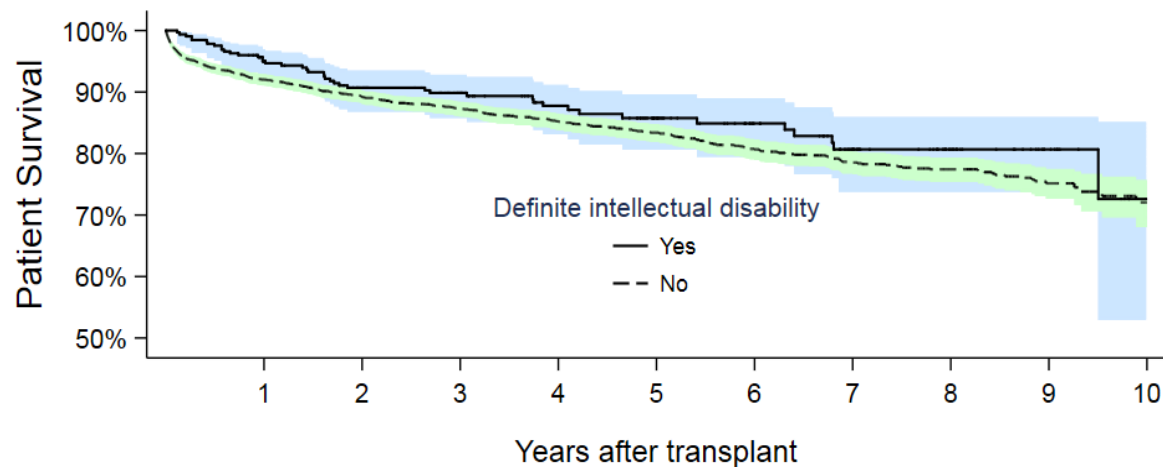
Levenson JL, Olbrisch ME. *Psychosomatics* 1992

Wall et al. *Ped Transp* 2020.

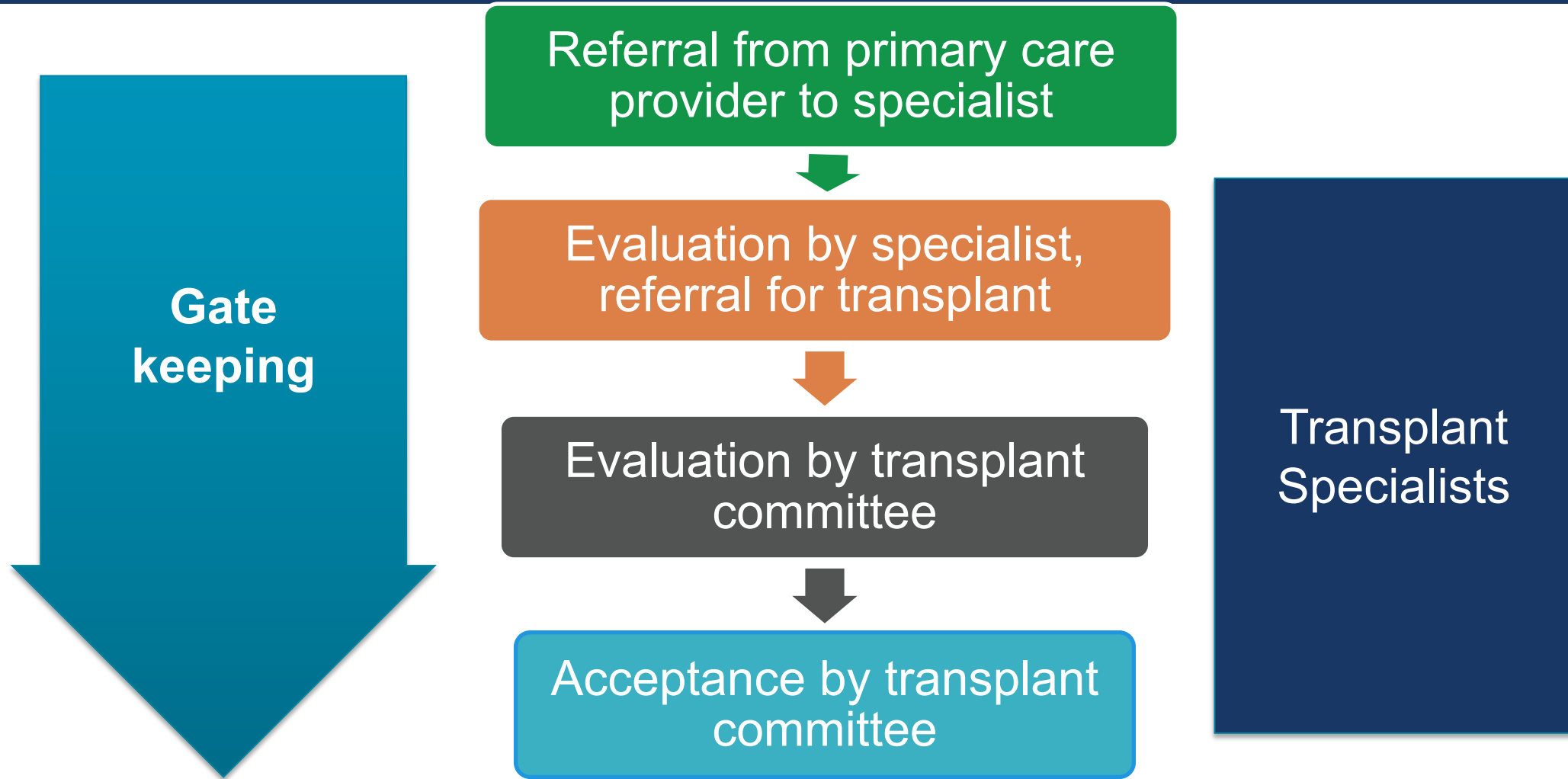
Long-term recipient survival: ID vs. Not

2008-2018

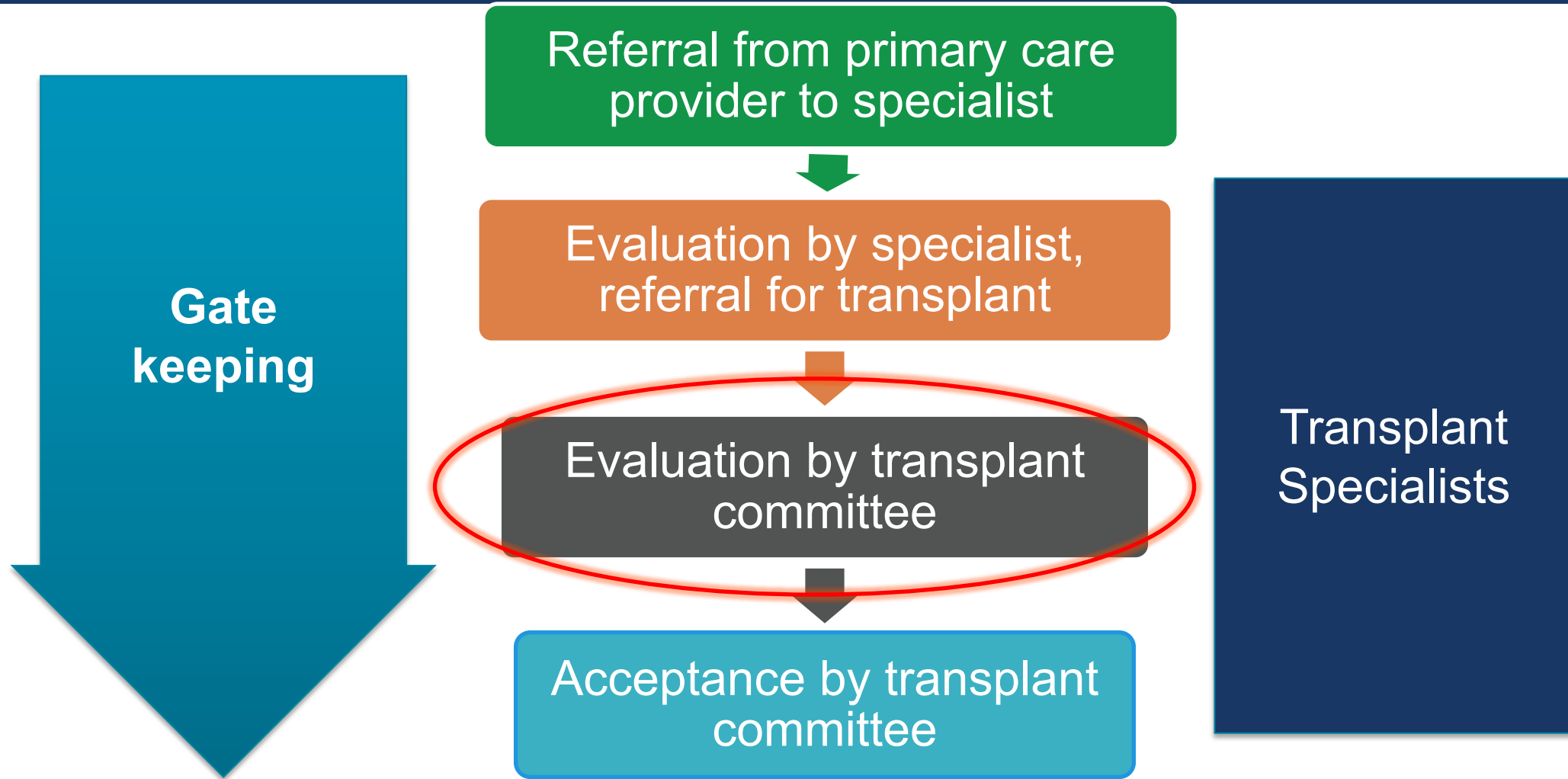
- Kidney: 594 (9%)
- Liver 318 (7%)
- Heart 324 (9%)



Barrier: The transplant approval process



Barrier: The transplant approval process



How we can do better: Reconsider Gatekeeping

- Open the closed process of transplant referral and evaluation
 - Boston Children's Protocol
- Standardize evaluation
 - Kidney Disease Improving Global Outcomes (KDIGO) Clinical Practice Guideline on the Evaluation and Management of Candidates for Kidney Transplantation
 - Reconsider its purpose

Kamin DS et al. *Am J Transplant.* 2016
Chadban SJ et al. *Transplantation* 2020

Arguments to **exclude** patients with intellectual disability as organ transplant candidates

1. Poorer graft and patient survival
2. Concern about the long-term future of candidates with severe ID who receive a transplant
3. Other, intellectually intact, candidates will suffer as a result of patients with severe ID receiving transplants

Wightman *Pediatr Transplant* 2017
Wightman et al. *Pediatr Transplant* 2018



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