



# Disability Policy Developments in Washington

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# Keeping All Students Safe Act

- ▶ Students with disabilities and students of color (as well as students with disabilities of color) are disproportionately subject to restraint and seclusion.
- ▶ Approximately one out of every 100 students with disabilities was restrained or subject to seclusion in the 2013-14 school year, meaning that almost 70,000 students with disabilities have been subject to this practice, often more than once.
- ▶ Students with disabilities (served by IDEA) represent 12% of the student population, but 58% of those placed in seclusion or involuntary confinement, and 75% of those physically restrained at school to immobilize them or reduce their ability to move freely.
- ▶ Keeping All Students Safe Act would prohibit seclusion and aversives while limiting restraint to emergencies, enhancing parental rights re: notification and other requirements

# Money Follows the Person Reauthorization

- ▶ Since 2005, the Money Follows the Person program has helped over 80,000 seniors and people with disabilities leave institutions and nursing homes for the community;
- ▶ MFP provides states with 100% federal financing for the first year after they leave an institution;
- ▶ Just re-authorized for 3 months, advocates fighting for longer reauthorization now.

# Home and Community Based Settings Rule

- ▶ Issued in 2014, provides for minimum standards for Home and Community Based Services;
- ▶ Designed to maximize autonomy, privacy and personal control over services;
- ▶ More robust standards for provider-owned and controlled residential settings;
- ▶ Heightened Scrutiny Process;
- ▶ Requires every state to meet these standards by 2022;

# Home and Community Based Settings Rule

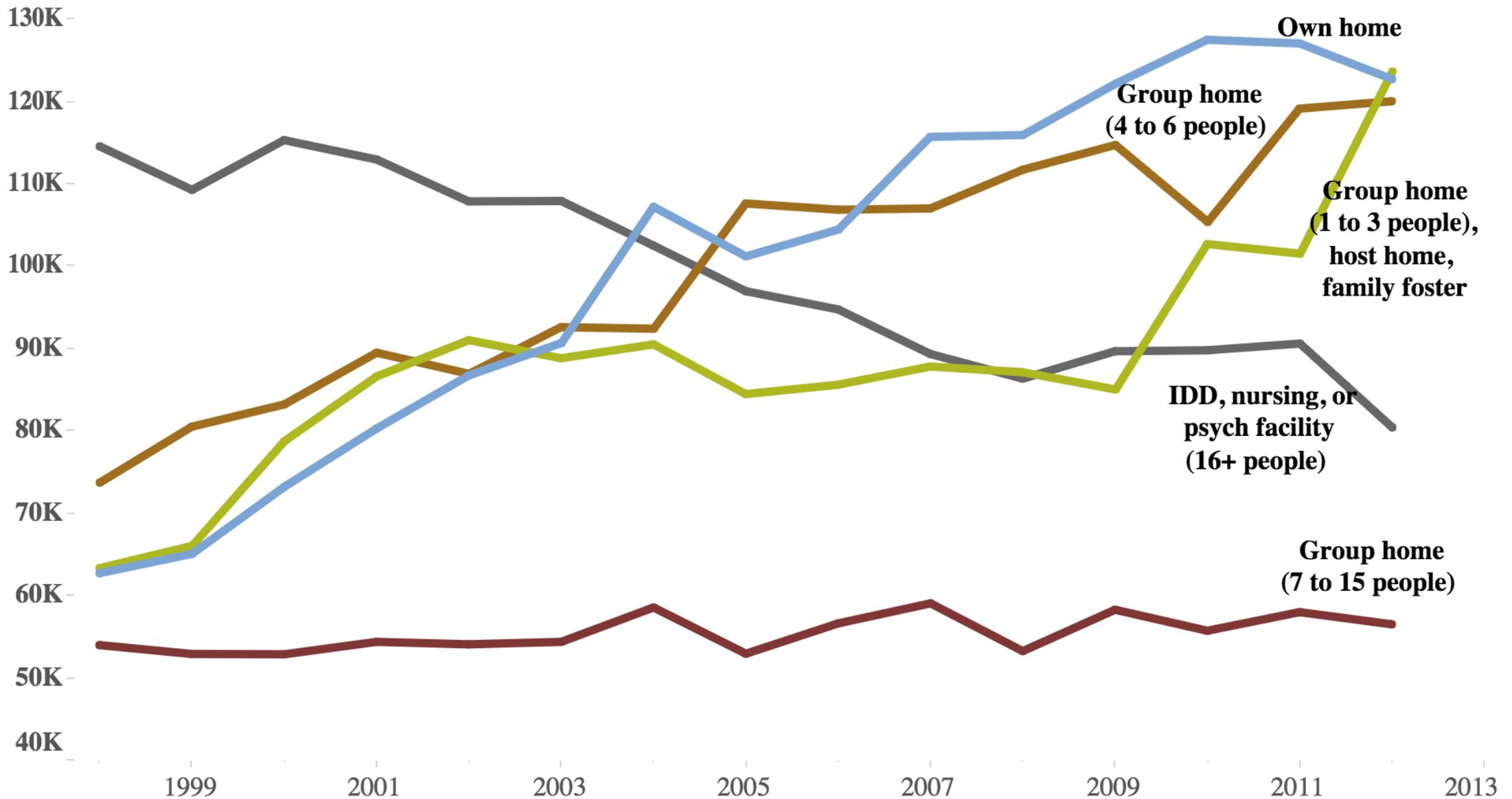
- The setting is integrated in and supports full access to the greater community;
- Is selected by the individual from among setting options;
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizes autonomy and independence in making life choices; and
- Facilitates choice regarding services and who provides them.

# Provider-Owned and Controlled Residential Setting Requirements

- The individual has a lease or other legally enforceable agreement providing similar protections;
- The individual has privacy in their unit including lockable doors, choice of roommates and
- freedom to furnish or decorate the unit;
- The individual controls his/her own schedule including access to food at any time;
- The individual can have visitors at any time; and
- The setting is physically accessible.
- An individualized exceptions process exists



# Change in the size and type of residence for people with IDD who did not live in the home of a family member: US estimates between 1998 and 2012



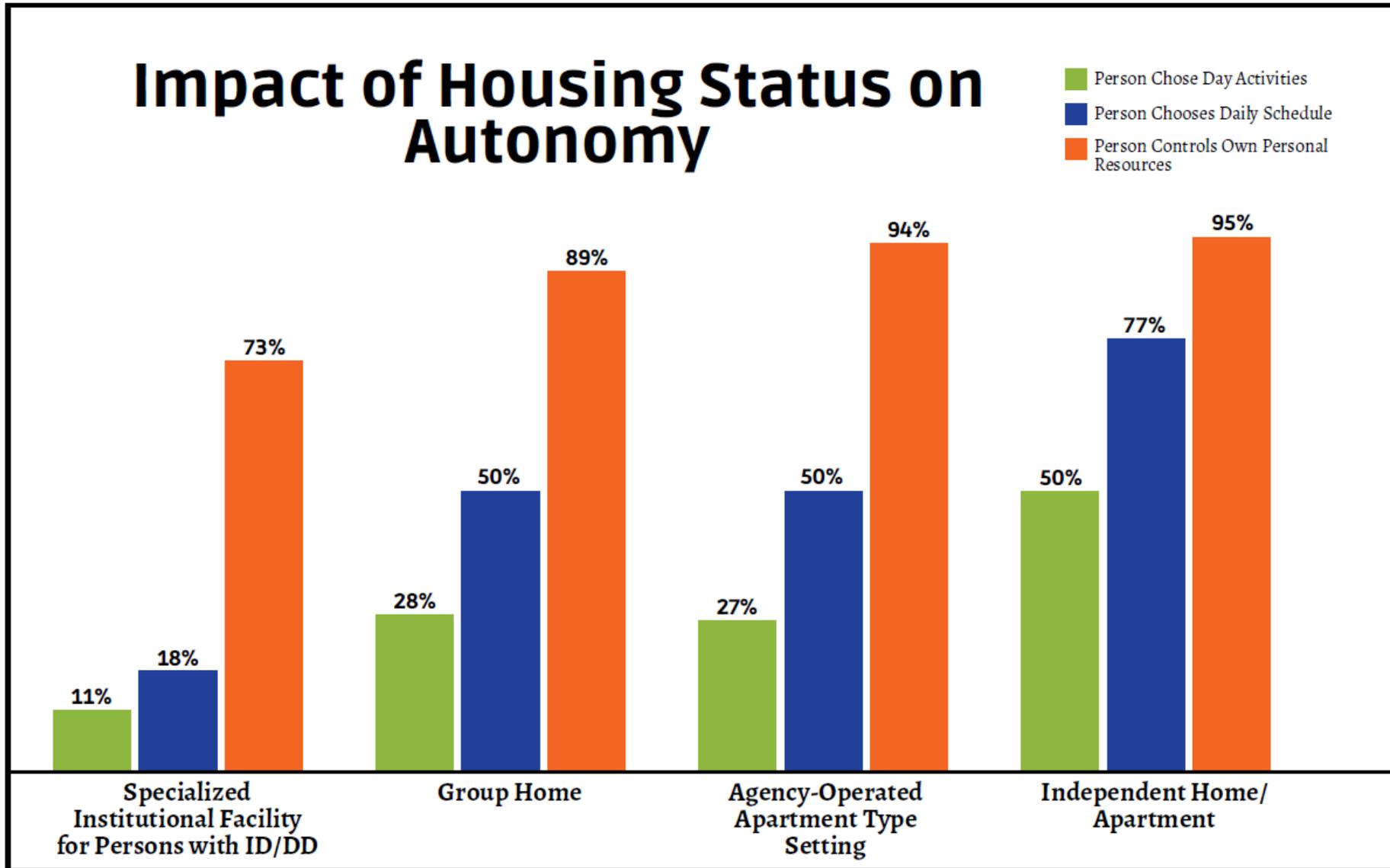


Figure 3. Source: National Core Indicators, <http://www.nationalcoreindicators.org/charts>

# Impact of Housing Status on Employment

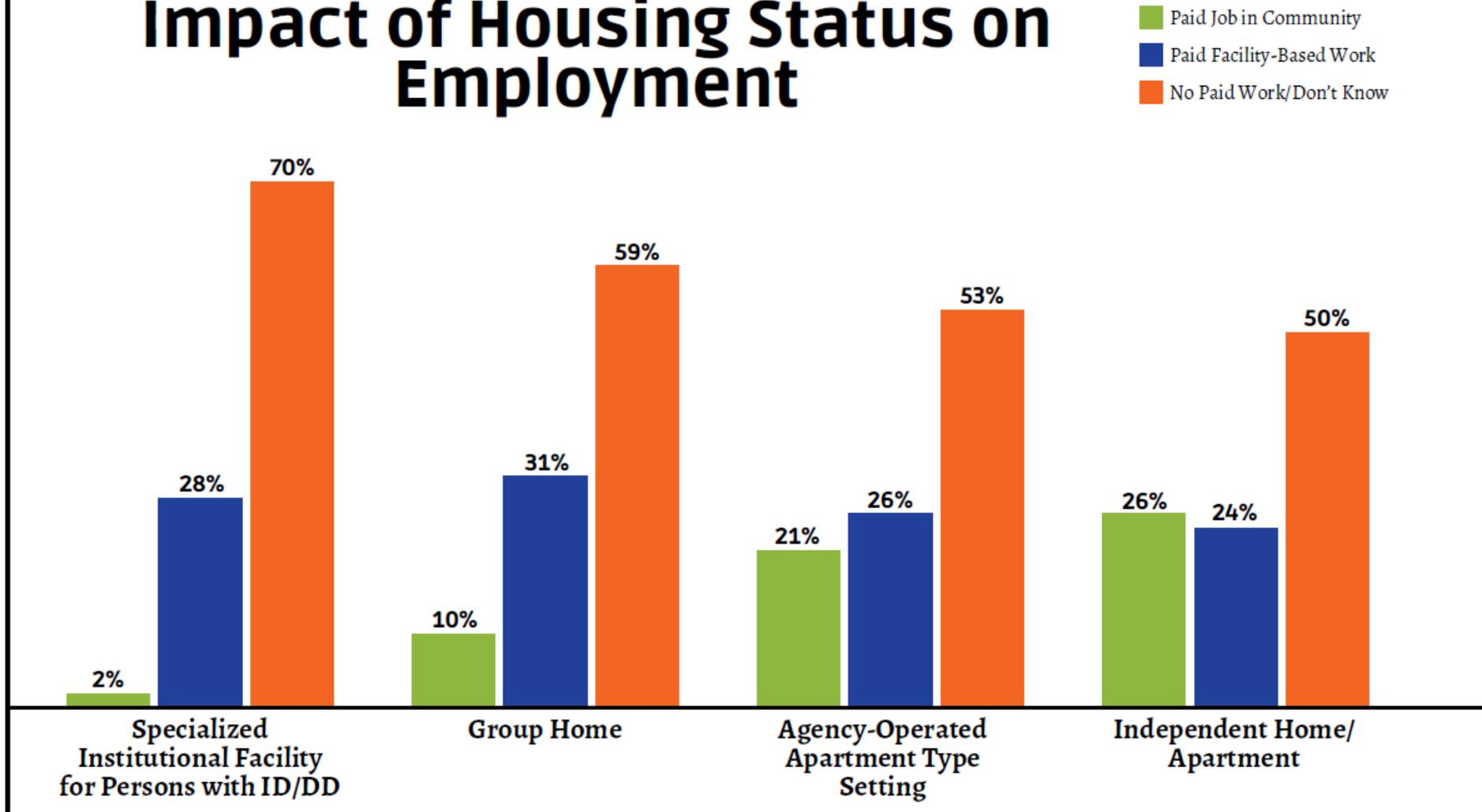


Figure 1. Source: National Core Indicators, <http://www.nationalcoreindicators.org/charts>

# Drug Pricing Discussions

- ▶ Access Restrictions Being Advocated as a Means of Reducing Drug Pricing;
- ▶ Perils of Medicare and Medicaid Negotiation;
- ▶ Controversies surrounding the Quality Adjusted Life Year (QALY);
- ▶ Alternative approaches exist:
  - ▶ Intellectual Property Reform;
  - ▶ Accelerating Generics and Biosimilars;

# QALYs as a Means of Measuring Quality

- ▶ Measure of disease burden and treatment efficacy in mitigating it;
- ▶ 1 QALY = 1 year in 'perfect health',
- ▶ 0 QALY = Death
- ▶  $0 < x < 1$  = Disabled or sick life

# QALYs and Disability Weights

- ▶ **Time Trade Off (TTO):** Survey respondents choose between living w/ a disability or illness for a period of time – or living in perfect health for a shorter period of time.
- ▶ **Standard gamble (SG):** Survey respondents pick between remaining w/ a disability or illness or choosing a medical procedure that might cure them or might kill them.
- ▶ **Visual Analogue Scale (VAS):** Survey respondents weight a disability or illness from 0 to 100, with 0 being death and 100 being perfect health.
- ▶ Using of QALYs at population level requires developing weights by surveying the (mostly non-disabled) general population

# Problems with QALYs

- ▶ Under population survey models, the non-disabled population may systematically overestimate the burden of life with disability.
  - ▶ Research suggests a majority of American public says they would rather have HIV than be blind (Scott, 2016).
- ▶ Common QALY measure (EuroQol-5D) rates inflammatory arthritis as “worse than death” (Harrison, 2009).
  - ▶ Significant variation between TTO and VAS quality of life assessments reported under EuroQol-5D
- ▶ Under models where PWD self-report QoL, well supported people with disabilities who report relatively high levels of quality of life due to access to adequate support may find it very hard to demonstrate sufficient gains in QoL due to treatment efficacy.