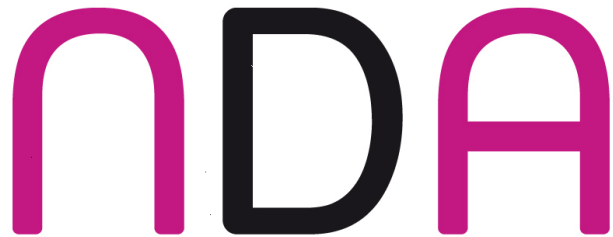


Translating research into policy

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Head of Policy and Public Affairs



Údarás Náisiúnta Míchumais
National Disability Authority

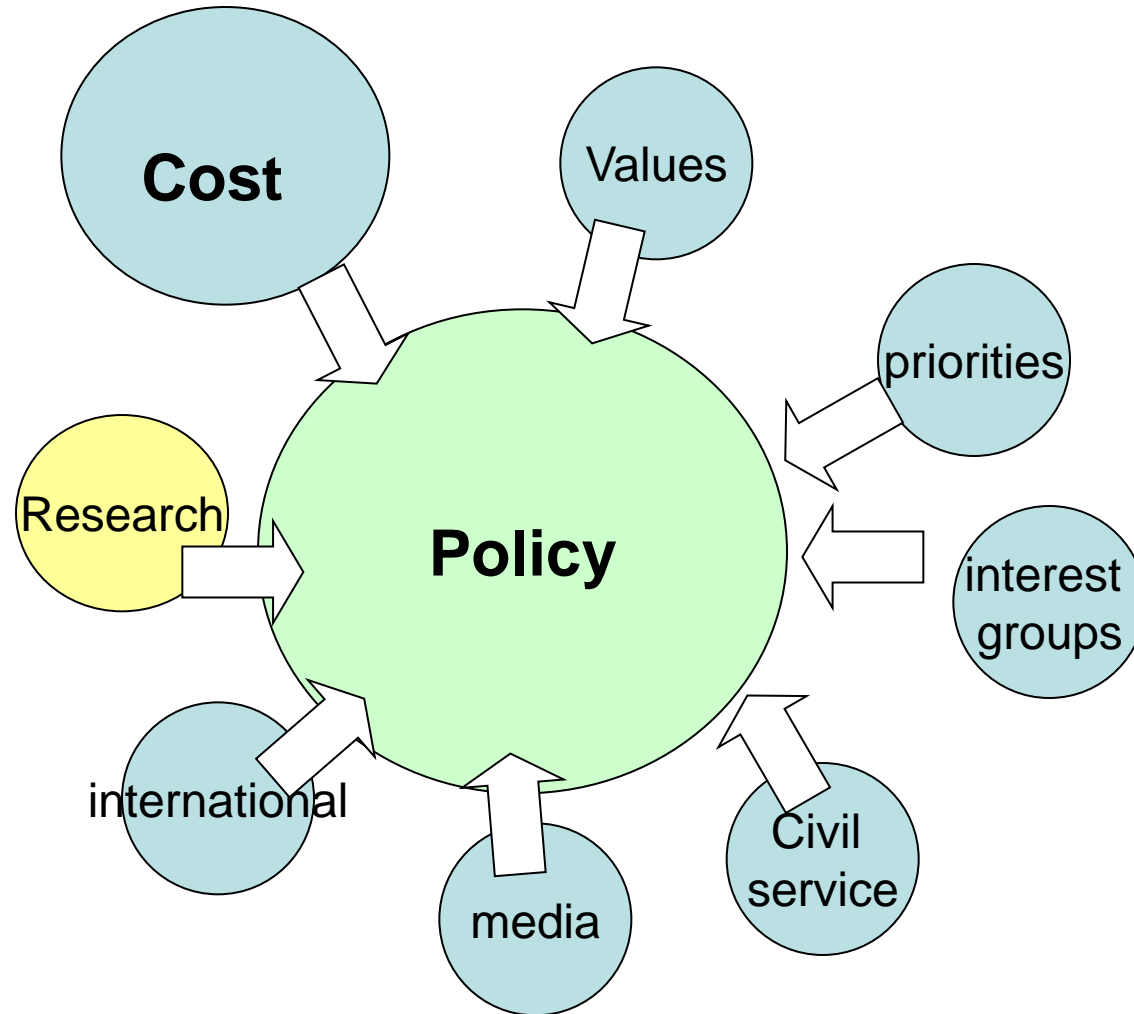
The National Disability Authority

- the independent state body providing expert advice on disability policy and practice to the Minister
- Statutory functions include
 - Advice and information
 - Research and statistics
 - Standards development
 - Centre of Excellence in Universal Design

Outline

- The policy process
- Research to policy – what works
- Kinds of evidence
- Examples in practice:
 - New models of services and supports
 - Closing our institutions

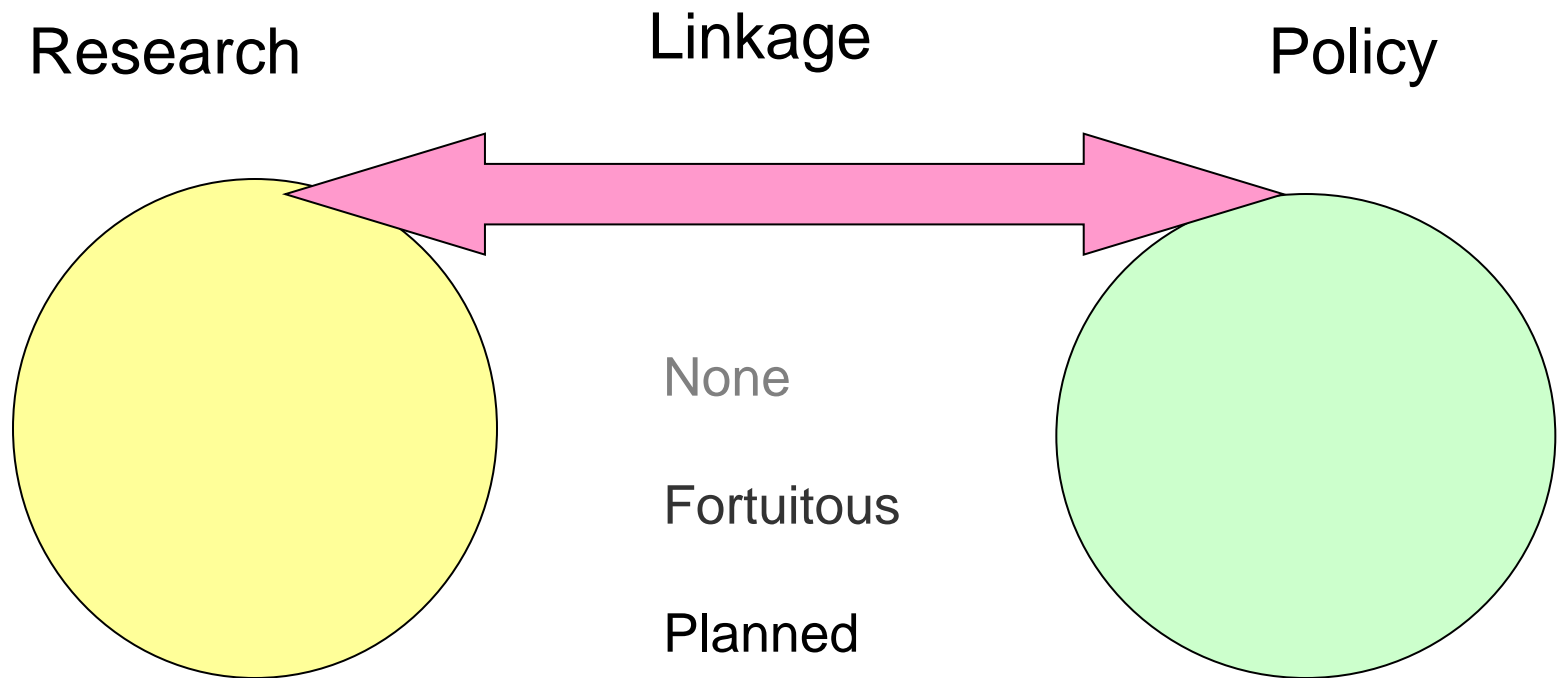
Research just one input into policy



Influences on policy

- Political values and priorities
- Programme for Government
- Cost
- Legacy of the current system
- Interest groups – providers, staff, families, service users, affected towns...
- Public service
- Media
- Standards and regulation, international obligations
- Research evidence

Research into policy



Research into policy – what works

Findings of EU funded study re education

- Activities, structures, systems to link research and policy
- Research ‘fit for purpose’ – quality, relevance, availability
 - Involve policymakers in setting research agenda
 - Systematic reviews of state of the evidence
- Capacity building of researchers and policymakers across evidence-to-policy spectrum

What makes it likely research will be used

Findings of systematic reviews in health sector

- Interaction between researchers and policymakers
- Timeliness
- Policymaker attitudes towards research evidence
- Policymaker skills and expertise
- Policy networks and trust in researchers
- Negatives:
 - lack of perceived relevance
 - use of jargon
 - publications aimed at a scholarly audience

NDA quality criteria for research

Criteria include:

- addresses the issues policymakers are grappling with
- illuminates strategies and examples of best practice in Ireland and abroad
- the research design addresses the policy or practice question under investigation
- research is developed in collaboration with the end users
- delivered in a timely fashion
- presented in a language and style that is readily understood
- rigorously objective and factual

Kinds of evidence

- Evidence v. theory, opinion
- Facts and figures
- Qualitative studies
- What works
 - Before and after comparisons, or matched comparisons
 - Working models (Ireland or elsewhere)
- Outcomes - lived experience of people with disabilities
- Research that speaks to policy – valid, honest, plain English, knows context, findings inform conclusions, problem-solving

Evidence-informed policy 1

Disability Policy Review

From

- Services →
- Focus on inputs →
- Block grants →
- Institutions →
- One size fits all →
- Service provider decides the shape of the services →

To

- Supports
- Focus on outcomes
- Individualised funding
- Community
- Diversity
- Joint decisions by service user, family, state and HSE

The evidence

- Expensive model of service – highly professionalised, segregated, wrap-around services
- People fit into model not other way round
 - 30% of over 40s with ID don't choose what they eat
 - 30% don't choose what they watch on TV
 - 45% no choice of when they go to bed
 - 75% no choice on where they live
- Not delivering what people with disabilities want – choice, control, 'ordinary lives in ordinary places'
- Individualised services deliver better quality
- See www.nda.ie --> research --> contemporary developments in disability services

Evidence-informed policy 2

Congregated Settings report

- Article 19 of the UNCRPD
 - Equal right to live in the community
 - Choices like others on where and with whom to live
 - Supports to live like others, promote inclusion
 - Participate in services and facilities for the mainstream population
- The current situation – site visits and data
- Research evidence on what gives best outcomes
- Good practice in other jurisdictions
- Case studies of individuals who had moved
- Demonstration projects in Ireland

What the evidence showed

- the current situation

- 75% people are 15 years + living in the centre
- Physically isolated from community
- Limited contact with family
- In last decade 620 had moved out but 700 moved in
- 25% lived 4 or more to a bedroom. 2-4 ft between beds
- 25% no day programme
- Lack of privacy and dignity
- *20 older people with severe disability, one accessible shower and 2 washbasins*
- Huge variation in cost per head

Moving to the community

What research tells us about what works

- 30 years of studies show that quality of life better in the community on virtually all measures
- Dispersed housing better than clusters
- Smaller is better – group homes of 4 or less work better than larger ones
- “people living with only partial staff support appear to conduct their lives more independently than do people living with constant staff support. This is not due to differences in their independent capability but to the inhibiting effect of staff presence” - Felce

Moving to the community

Research findings - what to look out for

- Don't let move to community result in mini-institutions – staff retraining for new roles is vital
- People living in community get fewer health checks – need an active programme to ensure they are included
- Build links into community – people may be isolated although located within community
- Join the dots

Next steps in disability policy

- Keep policy focused on what the evidence shows
- NDA research in train to inform the next stage of disability service reform
 - Resource allocation models
 - Natural community supports
 - Systems to deliver assistive technology
 - Assessment of need
 - Accessible mainstream health services

Some references on research-to-policy

- NESF (2005) Evidence-based policymaking
- Gough, Tripley, Kenny and Buk Berge (2011) Evidence-informed policymaking in education in Europe
<http://www.eipee.eu/LinkClick.aspx?fileticket=-QZjrftXa0Y%3D&tabid=2510&language=en-GB>
- Lavis JN, Davies HTO, Oxman A, Denis JL, Golden-Biddle K, Ferlie E: Towards systematic reviews that inform healthcare management and policymaking. *J Health Serv Res Policy* 2005, 10:35-48.
- Innvaer S, Vist G, Trommald M, Oxman A: Health policy-makers' perceptions of their use of evidence: a systematic review. *J Health Serv Res Policy* 2002, 7:239-44.