

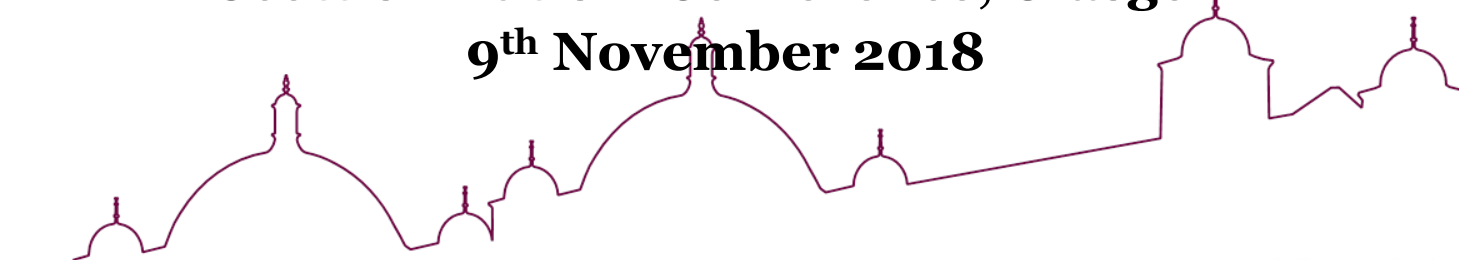
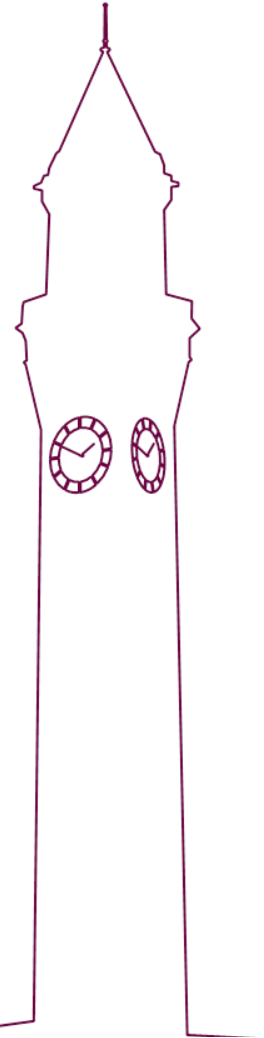
# **Robustness, reliability, and reflexivity in autism research for informing policy: lessons from the Benchmarking Autism Services Efficacy (BASE) report**

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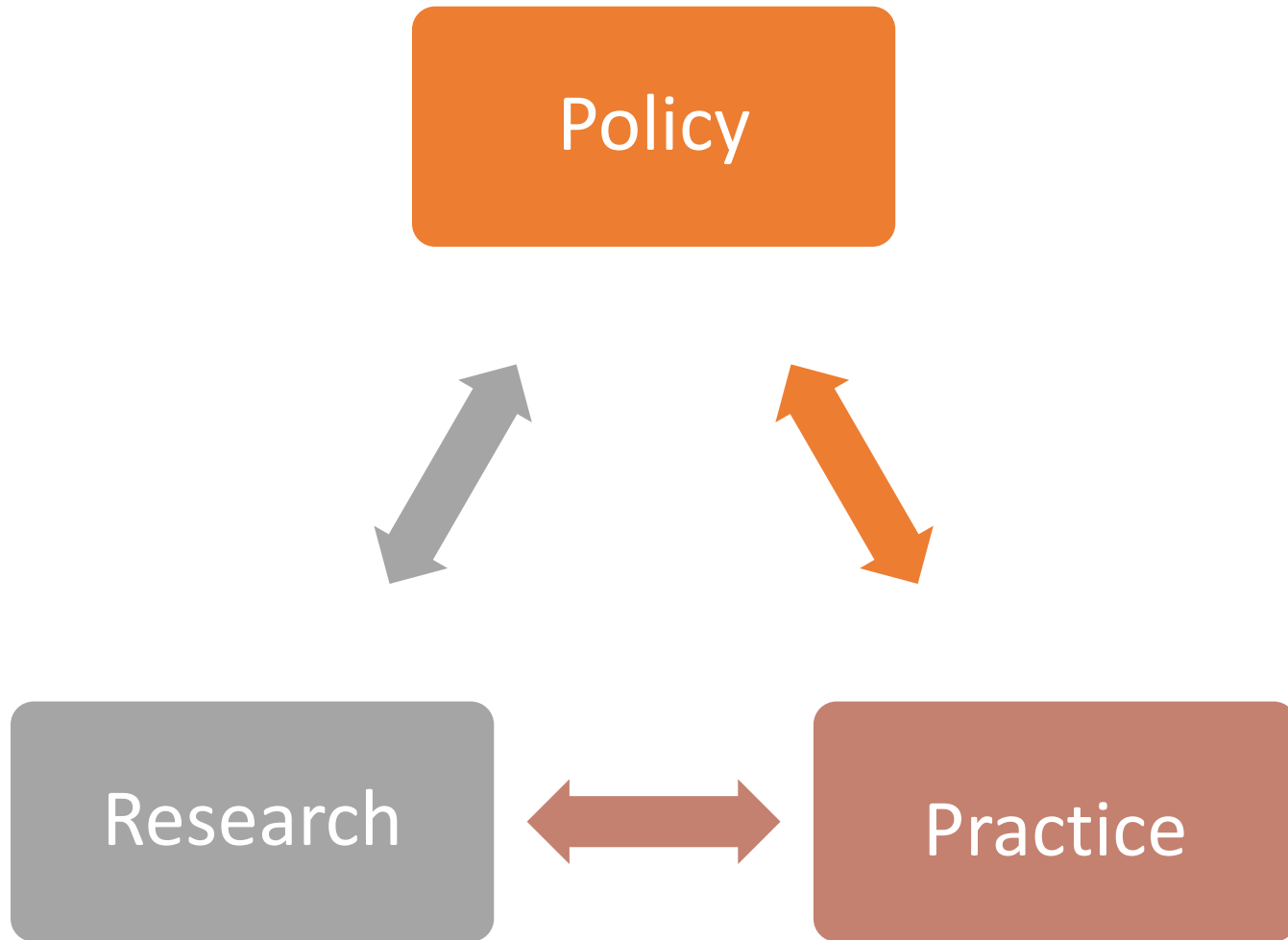
**Scottish Autism Conference, Glasgow  
9<sup>th</sup> November 2018**

**THE JOHN AND LORNA WING FOUNDATION**

*supporting autism research*



# What should we expect from research that aims to inform policy and practice?



# 'Benchmarking Autism Services Efficacy,' (BASE) report (Dillenburger, McKerr, and Jordan, 2015)

Literature review, survey, secondary data analysis, interviews & focus groups, summary and recommendations



Funded by the Office of the First Minister and Deputy First Minister (OFMDFM), Northern Ireland.

# The purpose of BASE...

“...was to establish how to help individuals with Autism Spectrum Disorder out of poverty by promoting social inclusion” (Vol.2, p.6).

# And...

“The BASE report provides baseline data regarding individuals with autism and it sets benchmarks against which the effect of the Autism Act (Northern Ireland) 2011 and associated Autism Spectrum Disorder (ASD) strategy can be measured” (Volume 5, p.5).

# Our task

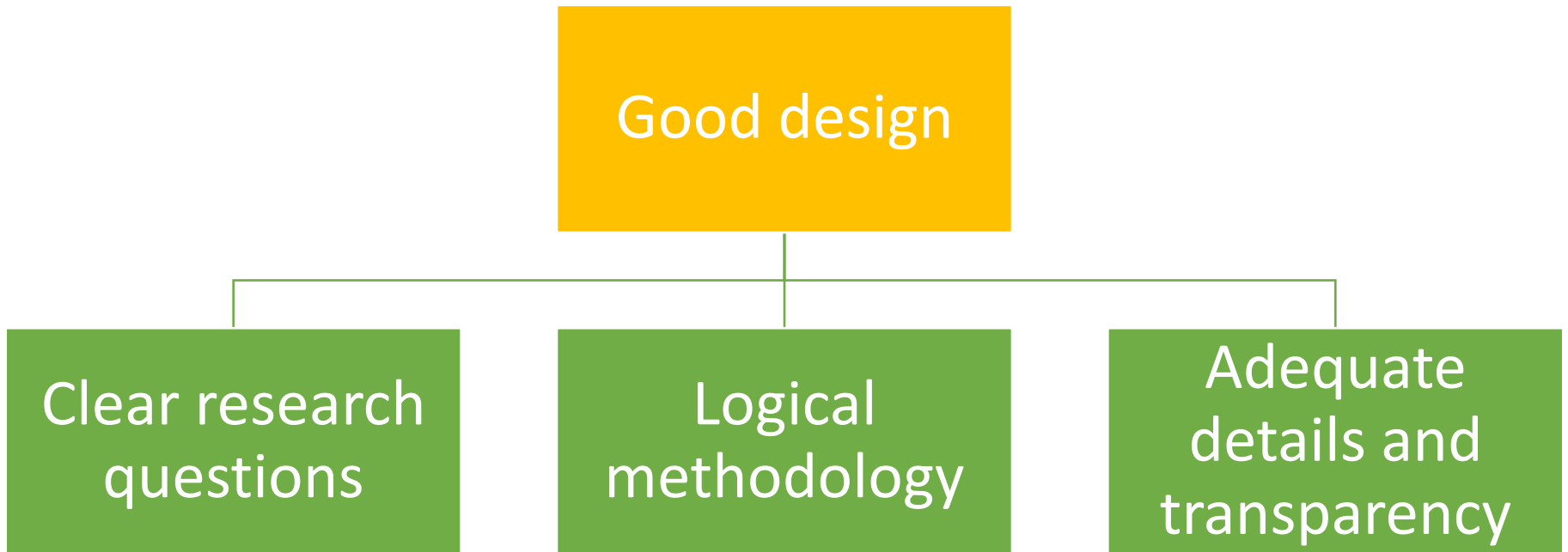
Given the potential for the BASE report to influence policy and practice we were commissioned by the John and Lorna Wing Foundation to independently review the report.

RQ: Were the conclusions of the BASE report (2015) scientifically grounded and based on a robust enough methodology to be used by policy makers to make decisions or take actions in respect of children, young people and adults with autism?

# Methodology

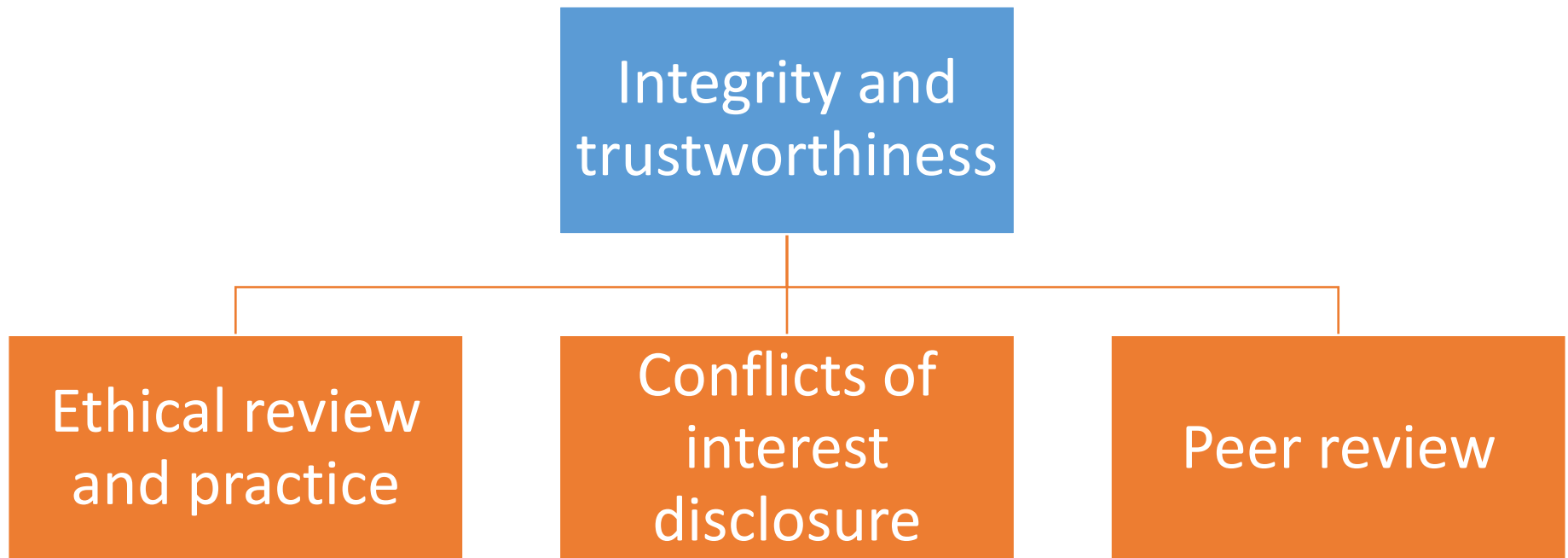


# High quality research needs...

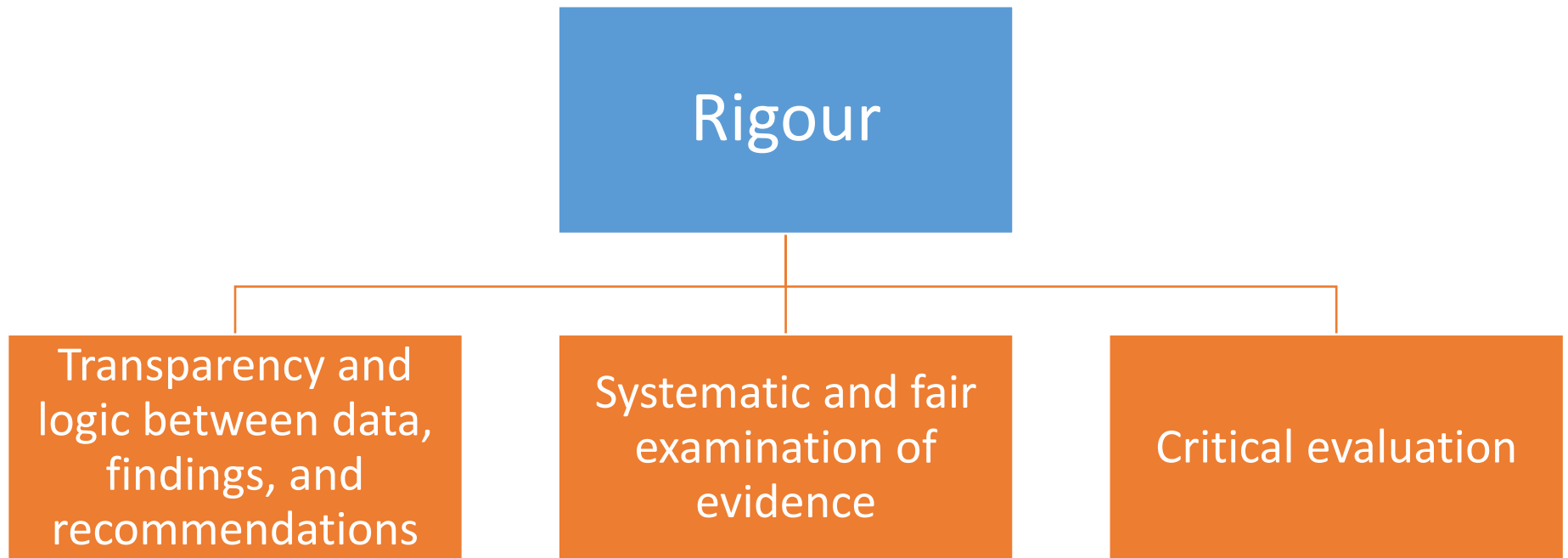




# High quality research needs...



# High quality research needs...



# Strengths of the BASE report: *‘a major undertaking’*

- A wide lens is taken on service provision (and related policies) for people on the autism spectrum, and their families.
- A welcome approach compared to narrow views or specific approaches to intervention.
- Strong survey design with systematic sampling (Vol. 2).
- Comprehensive secondary data analysis of children on the spectrum, and families, in NI (Vol. 3).
- The inclusion of the views and experiences of adults with autism is a strength (Vol. 4).

# Limitations: *'serious concerns'*

- Did not specify any research questions to guide and shape the research.
- Key terminology not defined e.g. 'poverty, poverty trap, vulnerability, and social exclusion.'
- Clarity missing on the choice and procedural aspects of methodology.
- Lack of transparency between data, findings, and recommendations with large jumps or tenuous links made.

# Limitations

- Little evidence of systematic examination of the research evidence.
- No assessment of its validity, quality, results, or relevance before using it to make recommendations for policy.
- The researchers failed to make their assumptions and influences clear leading to biased reporting.
- This lack of audit trail led reviewers to question many of the conclusions drawn throughout the separate volumes.

# Overall conclusion

“...the lack of objectivity, rigour and transparency in the BASE report overall mean that the findings and conclusions should not be taken at face value and should be re-evaluated in the light of the wide-ranging concerns raised by reviewers (p. 86)”.

Should the report be used to inform practice and policy?

# Department of Health (NI)

*The key findings and recommendations (from the Executive Summary) were discussed and accepted as nullifying any emanating from the original BASE research.*

*The lessons to be learnt regarding the need for clear guidelines for research grant applicants as well as the importance of expert objective sign off were also accepted.*

# Thank You to...

- The John and Lorna Wing Foundation who funded this.
- Autism Northern Ireland, who recommended that the scientific review should be undertaken.
- The peer reviewers of the report: Professors Pat Howlin and Connie Kasari.
- The peer reviewers of the volumes: Professors Graeme Douglas, Neil Humphrey, Melanie Nind, Jill Porter, Emma Smith and Patrick Sturgis, and Drs Abigail Knight and Samantha Parsons.
- Claire Robson: administrative support.

Our scientific review of the report is available to download here:

[https://www.researchgate.net/publication/321533925\\_Scientific\\_review\\_of\\_the\\_'Benchmarking\\_Autism\\_Services\\_Efficacy'\\_BASE\\_report\\_2015](https://www.researchgate.net/publication/321533925_Scientific_review_of_the_'Benchmarking_Autism_Services_Efficacy'_BASE_report_2015)



# Recommendations

There needs to be an appropriately designed and conducted systematic literature review that is carried out to address core research questions relating to poverty and wellbeing of individuals with autism and their families.

A survey should be conducted with service providers to understand whether there is indeed a failure to implement aspects of practice recommended or mandated in existing policy documents. Autistic people and their families should be included in this research from the outset.

# Recommendations

A clearly framed analysis should be commissioned of the Northern Ireland Life and Times (NILT) data (excluding ambiguously phrased questions) that addresses specific research questions and incorporates more sophisticated planned analyses in order to understand the possible links between independent and dependent variables.

# Recommendations

Further analysis should be undertaken of the secondary datasets. These should incorporate statistical significance for comparisons made, use a set of researchable questions to guide the analysis, with transparent explanation of where measures were taken from, and with coherent reporting of findings and careful presentation of figures and graphics.

# Recommendations

In order to fully understand and represent the voices of autism stakeholders, there needs to be a more robust and larger scale qualitative study that enables participation from a wider range of people. More stakeholders need to be included in qualitative methods that support a range of communication preferences and needs.

There would be value in undertaking an audit of the range of training courses and resources that are currently available for staff, autistic people and their families in Northern Ireland, including those available by distance learning.