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Putting together the data jigsaw: Linking data on children and young people with SEND

Learning from local areas

28th September 2023

Dr. Sarah Martin-Denham, Associate Professor of Care and Education, Sunderland University
Anne Pinney, Research Consultant & True Colours Data Champion



Introduction



#pullupachair -
films co-created
with children,
young people and
parents affected
by exclusion from
school [access
here](#)

Understanding the needs of disabled children with complex needs or life-limiting conditions

WHAT CAN WE LEARN FROM NATIONAL DATA?

Special educational needs

A mainstream issue

Data Bulletin No. 1

1. Introduction: The data challenge
2. Just launched: CDC's 0-25 SEND data dashboard
3. Improvements in health data: Community Services Dataset and Paediatric Disability data
4. Case study: Data-linking in Middlesbrough
5. Hot off the press: New SEND statistics

Sunderland and South Tyneside SEND Data Linkage projects (2021-23)



- **Lifestart** (Local Data Accelerator Fund) exploring the needs, pathways, risk and protective factors of children and young people excluded from school.
- **British Academy of Childhood Disability: Castang Award 2022:** Exploring if children and young people with learning difficulties are identified by health, education and social care.
- **UKRI Policy Support Fund** - University of Sunderland (Jan-Jul 2023)

Putting together the data jigsaw: linking administrative data on children with SEND

UKRI Policy Support Fund, University of Sunderland (Jan-Jul 2023)



1. FOI to LAs and ICBs to map extent of data linkage of children's data
2. Policy workshop, May 2023
3. Interviews with 6 local areas exploring barriers, enablers and outcomes

Today's workshop

1. What is data linkage?
2. Policy context
3. How many local authorities and ICBs link data on children and young people with SEND?
4. How many of you are doing this?
5. What are the benefits of data linkage?
6. What are the barriers and enablers to data linkage?
7. What would help your organisation link data?

What is data linkage?

Data linkage combines data from different sources that relate to the same person to create a new, enhanced data resource.

Data linkage involves using a unique identifier such as an NHS number (or matching personal details, such as name, date of birth and postcode) to identify the same individuals or groups across different datasets. This needs to be done securely and consent may be required.

Data linking, data matching or data sharing?

Policy commitments on data-sharing and linking (children & young people)

Supporting Families programme

SEND review
March 2022

Independent Review on Children's Social Care
May 2022

Data and Digital taskforce

Improving multi-agency information sharing
July 2023



Joined up data in government: the future of data linking methods

Government Analysis Function/ONS Guidance, July 2021

“Being able to link data will be vital for enhancing our understanding of society, driving policy change for greater public good and minimising respondent burden.

Whilst there is a lot of data linkage taking place across government, this is often conducted in isolation with limited knowledge sharing. There needs to be a joined-up approach to ensure that data linkage is at the heart of improvements to official statistics.”

Endorsed by the [National Data Strategy](#) (DCMS & DSIT, 2022).

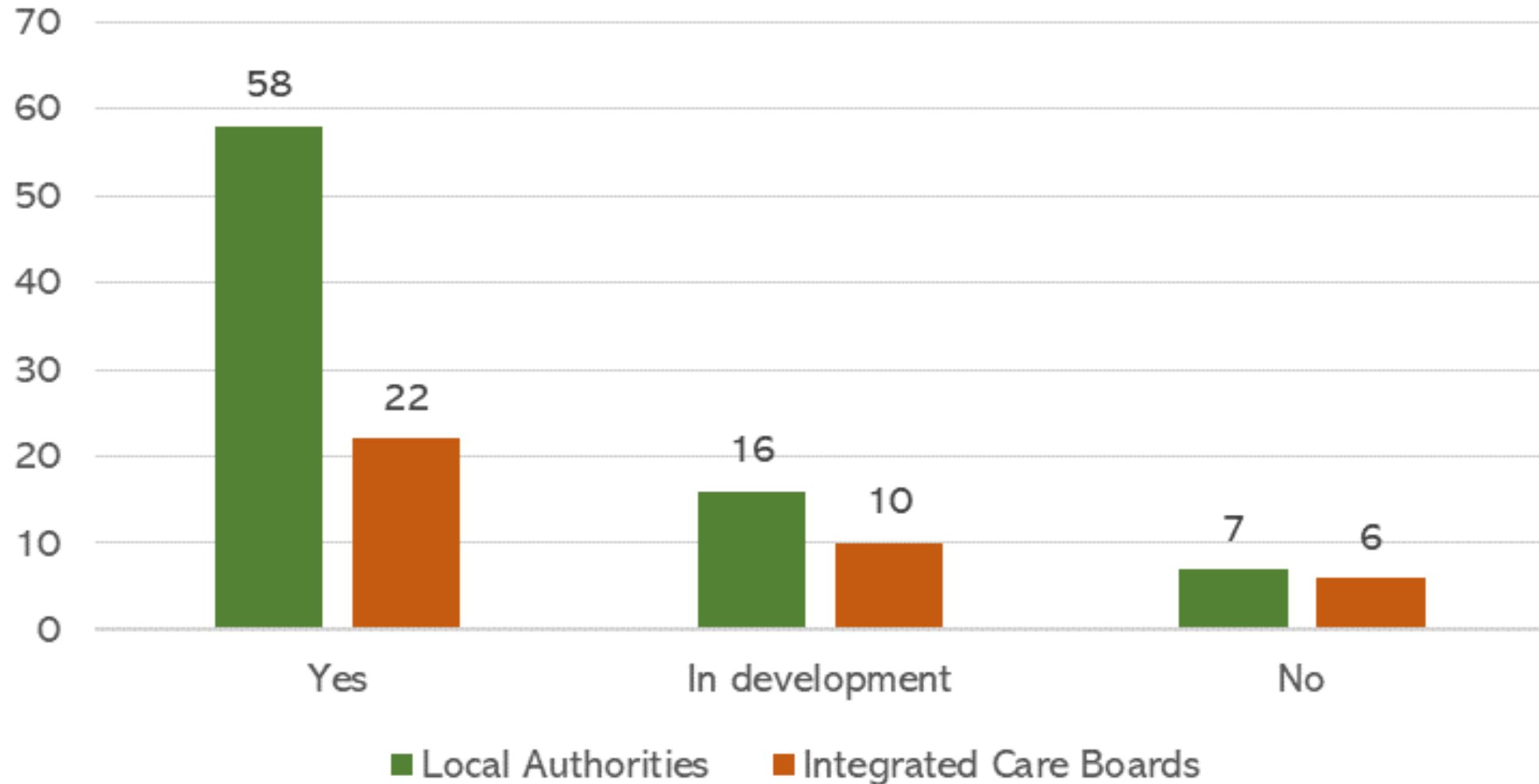
How many LAs and ICBs link data on children & young people with SEND? [FOI]

Comparing the extent of data linkage in LAs (N=95) and ICBs (N=38) through FOIs

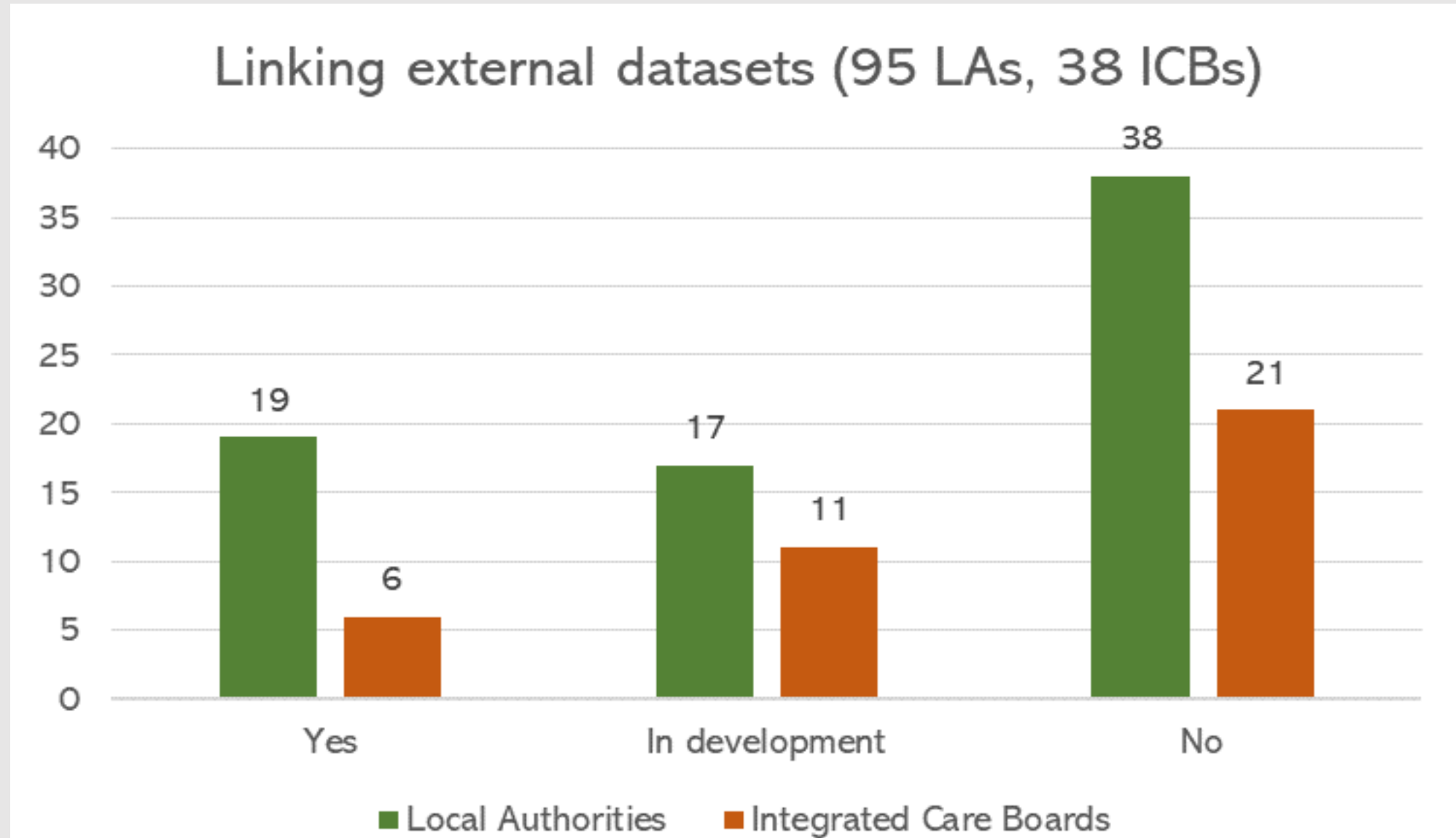
- The majority of LAs and ICBs were **linking their own internal datasets**, although a larger proportion of LAs were doing this than ICBs. For the LAs, this would be linking their social care and education datasets, while ICBs were linking healthcare datasets together.
- However, LAs and ICBs were **unlikely to be linking internal data with external datasets**.
- Those who were linking data were often **linking data on all CYP** in the area, including CYP with SEND. It is unclear whether LAs and ICBs were undertaking *specific* data linkage initiatives for these cohorts.
- A worrying finding was that the **Community Services Dataset** was only being linked by three LAs, despite containing crucial diagnostic information for childhood disabilities.
- Data linkage was most used for **strategic planning** and **data dashboards**. Among LAs, a surprising number were not using linked data for joint commissioning.

How many LAs and ICBs are linking internal datasets?

Linking internal datasets (95 LAs, 38 ICBs)

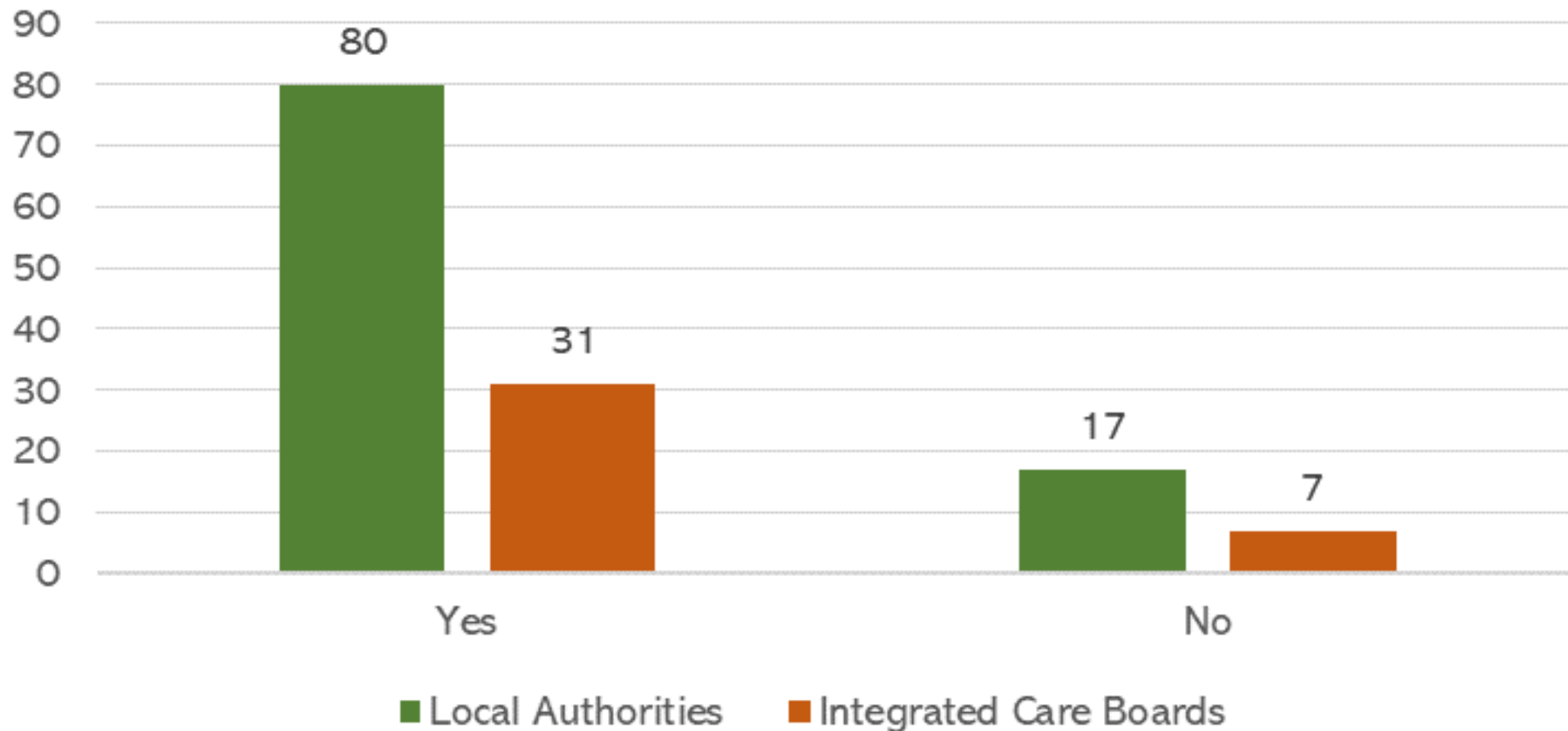


How many LAs and ICBs are linking internal datasets with external datasets?



How many LAs and ICBs are linking data for CYP with SEND?

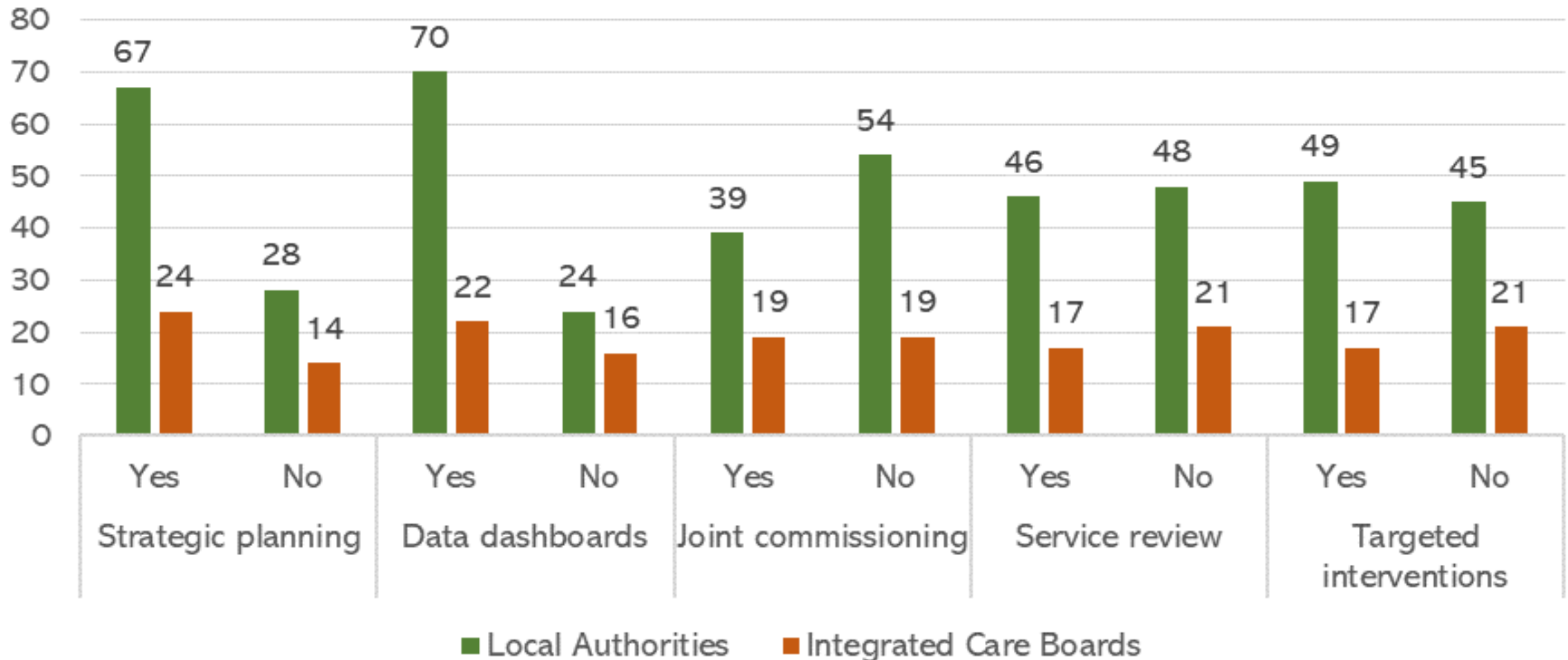
Linking data on CYP with SEND (95 LAs, 38 ICBs)



How are LAs and ICBs using linked data for CYP with SEND?



Uses for linked data (95 LAs, 38 ICBs)



Why link data on children & young people with SEND?

1. Informing JSNAs, joint commissioning & workforce planning
2. Understanding patterns of service use, pressure points & gaps in provision
3. Informing early intervention strategies
4. Informing targeted responses
5. Understanding impact and enabling a 'whole system' response
6. Strengthening partnership working, shared understanding and ownership of SEND.

How are you using your linked data?

What are the key benefits in your experience?

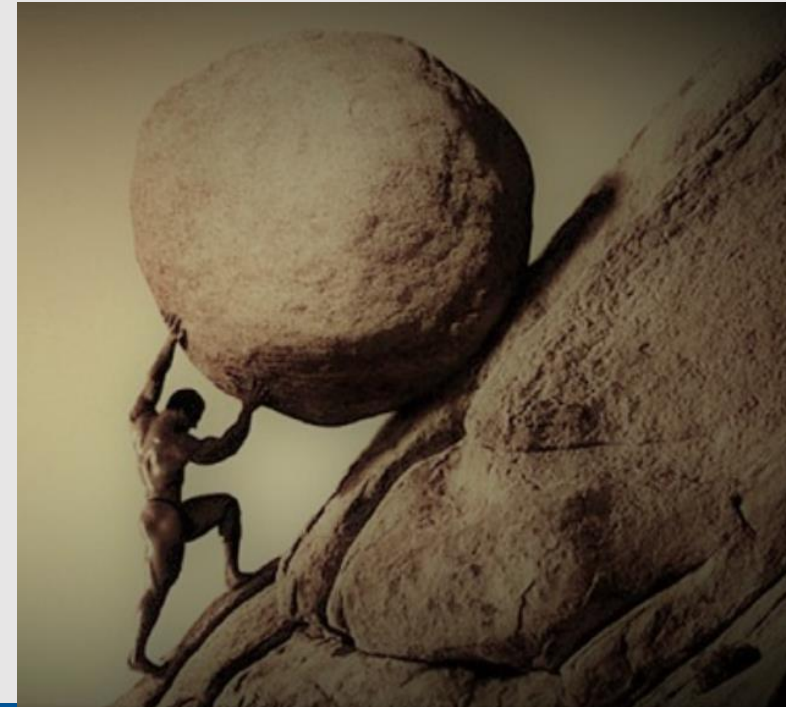


What are the barriers to linking children's data?

1. Health data: lack of knowledge or clear national expectations; lack of leverage; risk averse attitudes; differing boundaries & age ranges
2. Information governance (IG) hurdles
3. Data & digital: Lack of consistent identifier, data quality, incompatible systems, digital maturity
4. Cultural challenges – siloed working, fear of scrutiny
5. Resources – partnership working, data & digital capability, IG

Lifestart and BACD Castang Award projects: barriers

- Not knowing the hoops, processes and protocols
- IGARD (Independent Group Advising on the Release of Data)
- DSPT (Data Security and Protection Toolkit)
- DPIA (Data Protection Impact Assessment)
- ISA (Information Sharing Agreement)
- Unblocking dataflows
- Lack of unique identifier
- Lack of standardisation in data sets (variable titles)
- Issues with batch tracing (match rates)



What helps? Enabling factors

1. Senior strategic commitment, cross-cutting governance & scrutiny of data
2. Integrated team & systems, strong working relationships
3. Knowledge of health data, commissioning, contract management
4. Prior data linkage experience and capability.

What do you think would help local areas to make progress with SEND data linkage e.g.

- national policy
- research and information
- networking, sharing learning
- practical resources?

