

Tips for Parents and Guardians Considering Participation in Learning Disabilities Research

Participating in Research: What Do Parents and Guardians Want to Know?

Parents and guardians of children with learning disabilities want to participate in research. When considering participation in a research study, think about how the researchers answer the following questions:



What's in it for the researchers? They should communicate clearly what the study is about and what they hope to achieve.



What's in it for you? They should explain how your participation will make a difference.



What do they expect of you? They should describe the time and tasks involved in study participation.



Who will see your information? They should tell you who will access the data and how it will be kept confidential.



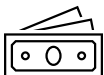
What if you are hesitant or uncomfortable? They should explain that participation is voluntary and that you are free to leave the study at any time.



Why do the researchers care? They may share their motivation – professional or personal - if appropriate.



How will they protect you and your children from research risks? Researchers should specify privacy and safety plans in the research protocol and explain what they are and what resources can help support them.



Is there a financial incentive for you? They may provide a gift card or stipend for participation.

Parents' and Guardians' Participation Throughout the Research Lifecycle

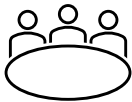
Parents and guardians can provide useful advice on all aspects of research projects. Consider how you might want to be involved in each of these activities.



Selecting research topics that matter to the community.



Promoting the dissemination and use of results.



Advising on whether participating in the study is feasible for the community.



Interpreting findings.



Designing or reviewing protocols and procedures.



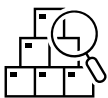
Participating in data collection and analysis.

How Do Parents and Guardians Know Which Information to Trust?

Making decisions can be confusing when there are so many opinions out there about learning disabilities. Here are some strategies you can use to find trustworthy information.



Where is the information coming from? Look for sources that are reliable, like a well-trained healthcare provider, reputable professional or advocacy organization, or well-known university.



Search for the same information from more than once source. When information comes up in several different sources, it is perceived to be more trustworthy.



Information may change as researchers learn more about conditions and strategies or approaches. You may need to keep asking questions.



Other parents and guardians mentioned these trusted sources: LDAamerica.org, dysgraphia.life, understood.org, mayoclinic.org, and healthychildren.org.