

2016 INTERNATIONAL  
AUTISM SPECTRUM DISORDER RESEARCH

# PORTFOLIO ANALYSIS REPORT





2016 INTERNATIONAL  
AUTISM SPECTRUM DISORDER RESEARCH

**PORTFOLIO ANALYSIS REPORT**

## **COVER DESIGN**

Medical Arts Branch, Office of Research Services, National Institutes of Health

## **COPYRIGHT INFORMATION**

All material appearing in this report is in the public domain and may be reproduced or copied. A suggested citation follows.

## **SUGGESTED CITATION**

Office of Autism Research Coordination, National Institute of Mental Health, Autistica, Canadian Institutes of Health Research, and Macquarie University. *2016 International Autism Spectrum Disorder Research Portfolio Analysis Report*. October 2019. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <https://iacc.hhs.gov/publications/international-portfolio-analysis/2016>

# Table of Contents

---

|                                                                                               |           |
|-----------------------------------------------------------------------------------------------|-----------|
| <b>Introduction.....</b>                                                                      | <b>1</b>  |
| Purpose and Goals for International Analysis.....                                             | 2         |
| Countries included in the International ASD Research Portfolio Analysis.....                  | 3         |
| IACC Strategic Plan Framework.....                                                            | 8         |
| <b>ASD Research Funding and Funders in 2016 .....</b>                                         | <b>11</b> |
| 2016 ASD Research Funding.....                                                                | 12        |
| 2016 ASD Research Funders in Each Country.....                                                | 13        |
| ASD Research Funding Provided by Each Funder in 2016 .....                                    | 15        |
| Institutions Receiving Research Funding in Each Country .....                                 | 20        |
| <b>Analysis of ASD Research Priority Areas in 2016 .....</b>                                  | <b>23</b> |
| ASD Research Priority Areas Funded in 2016.....                                               | 24        |
| Comparative Analysis of Each Country's ASD Research Portfolio by Research Priority Areas..... | 27        |
| Australia's 2016 Autism Research Portfolio .....                                              | 30        |
| Canada's 2016 Autism Research Portfolio.....                                                  | 33        |
| United Kingdom's 2016 Autism Research Portfolio.....                                          | 36        |
| United States' 2016 Autism Research Portfolio .....                                           | 39        |
| <b>Summary and Conclusion .....</b>                                                           | <b>43</b> |
| <b>Appendices .....</b>                                                                       | <b>45</b> |
| Appendix A: List of Acronyms .....                                                            | 46        |
| Appendix B: Methods.....                                                                      | 47        |
| Appendix C: Funder Mission Statements.....                                                    | 48        |
| <b>Contributors .....</b>                                                                     | <b>55</b> |



# Introduction

## Purpose and Goals for International Analysis

---

Over the past nine years in the United States (U.S.), the Office of Autism Research Coordination (OARC) at the National Institutes of Health (NIH) has published an annual national autism spectrum disorder (ASD) research portfolio analysis report. The report provides comprehensive information about autism research funding and helps monitor ASD research efforts across the country. Outside of the U.S., other countries have been supporting ASD research, but there has never been an effort to track global investment. To achieve a first assessment of global ASD research, four countries collaborated to compile and analyze funding of ASD research within their countries and assess the composition of each research portfolio. The comparison of portfolios revealed areas of emphasis, similarities, differences, and gaps across the portfolios. The analysis fostered international collaboration and identified global trends in ASD research funding in the hopes of accelerating and inspiring research that will benefit the autism community.

The purpose of this report is to present the current landscape of ASD research in the United States, the United Kingdom, Canada, and Australia. Information on ASD research funding was collected and analyzed by the OARC in the United States, Autistica in the United Kingdom, the Canadian Institutes of Health Research (CIHR) in Canada, and Macquarie University in Australia. The report will compare levels and types of investment among countries, such as where research is being funded, what types of agencies and organizations support ASD research, and what research areas received funding. The analysis of the 2016 international research portfolio sheds light on areas for future research partnerships and areas in need of additional support in order to create a global ASD research portfolio that comprehensively addresses the needs of people on the autism spectrum worldwide.

**Please note:** The terms “person with autism,” “person with ASD,” “autistic person,” and “person on the autism spectrum” are used interchangeably throughout this report. Some members of the autism community prefer one term, while others prefer another. We respect the different opinions within the community on the use of this language and do not intend to endorse any particular preference. In addition, the terms “autism” and “autism spectrum disorder (ASD)” are used interchangeably throughout this document unless otherwise noted.

## Countries included in the International ASD Research Portfolio Analysis

### United States

The United States is the largest global funder of ASD research. Within the U.S., both federal government agencies and private organizations provide funding for autism research. In addition, some ASD research initiatives are funded through public-private partnerships between federal agencies and private organizations. Starting in 2006, the U.S. government enacted a series of laws to bolster federal agency efforts related to ASD research, services and supports, and interagency coordination. The latest in this series, the Autism Collaboration, Accountability, Research, Education and Support (Autism CARES) Act of 2014 ([P.L. 113-157](#)) authorizes a variety of federal agency activities that support autism research, services, provider training, and surveillance programs. The Autism CARES Act also authorizes the [Interagency Autism Coordinating Committee \(IACC\)](#), an advisory body composed of federal officials from multiple U.S. government departments and agencies, as well as community stakeholders, including autistic adults, family members, leaders of autism research, advocacy, and service organizations. The broad membership of the IACC provides a diverse range of expertise and viewpoints to inform U.S. autism efforts. The IACC is charged with responsibilities including coordination of federal agency efforts, gathering public input, and providing collective advice and recommendations to government agencies on priorities for ASD research, services, and policy.

The IACC is required by the Autism CARES Act to develop and annually update a Strategic Plan for autism spectrum disorder that will provide guidance to government agencies and partner organizations on priorities for autism research, services, and policy. The Strategic Plan was

recently revised to the current edition, the [2016-2017 IACC Strategic Plan for Autism Spectrum Disorder](#), which describes progress across the different areas of ASD research and provides a set of 23 objectives that address research, services, and policy needs identified by the IACC using input gathered from public stakeholders and experts. OARC, the lead contributor of this global portfolio analysis report, manages the IACC and produces additional reports including an annual analysis of the U.S. autism research portfolio, the IACC Strategic Plan, the annual IACC Summary of Advances in ASD Research, and additional reports on federal government activities related to autism.

Prevalence estimates for autism in the U.S. are provided by the Centers for Disease Control and Prevention (CDC) through population-based ASD surveillance and research conducted by the Autism and Developmental Disabilities Monitoring (ADDM) Network. Since 2000, the ADDM surveillance has resulted in the most robust estimates to date of the prevalence of ASD in the U.S. Currently, the CDC estimates that about [1 in 59](#) 8-year old children in the U.S. have been identified with ASD. Several U.S. federal agencies and private organizations are investing in research to understand the causes and biology of autism, diagnosis and interventions, trajectories and outcomes, and how best to support individuals, families and communities affected by autism.

The National Institutes of Health (NIH) is the largest funder of autism research in the U.S. and globally, with an investment of \$281 million in 2018,<sup>1</sup> spanning research on diagnosis, underlying biology, risk factors, treatment, and services. Other major U.S. government funders of ASD

<sup>1</sup> NIH Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). [https://report.nih.gov/categorical\\_spending.aspx](https://report.nih.gov/categorical_spending.aspx)

research include the CDC, which supports research on surveillance, epidemiology, and early identification; the Health Resources and Services Administration (HRSA), which funds research on physical and behavioral health and services; the Department of Education (ED), which supports research on educational interventions and training for teachers; and the Department of Defense (DoD), which funds biomedical research on ASD and novel

## United Kingdom

The United Kingdom (U.K.) has supported autism research through the efforts of public body agencies and private, non-profit organizations for many years. The government has established the [Autism Act \(2009\)](#), which set out responsibilities for local authorities and the National Health Service (NHS) to improve services for autistic adults, including a diagnostic pathway in every area, training for key professionals, local plans and a local autism lead. Updated statutory guidance was published in 2015. Also, the government authorized the [‘Fulfilling and Rewarding Lives’ \(2010\)](#), later updated to [‘Think Autism’ \(2014\)](#), which is a national strategy for autistic adults. The implementation of the strategy is overseen at the senior level by a cross-departmental Adult Autism Programme Board, led by the Department of Health. In 2018, the implementation model of the Strategy was refreshed and an overarching objective to improve autistic people’s life expectancy was introduced. The Department of Health and Social Care has committed to review the Strategy in full in 2019. Following lobbying by Autistica and other autism charities, the UK’s NHS adopted autism (alongside heart disease, cancer and mental health) as a clinical priority for the first time in 2018. Also, the National Institute for Health and Care (NICE) Guidelines set out recommendations for local children’s services, including what pathways to diagnosis should look like and the types of support that should be available post-diagnosis.

treatments and interventions for people on the spectrum. The Simons Foundation, Autism Speaks, and the Autism Science Foundation are examples of private, non-profit organizations that also support autism research in the U.S. To date, based on an analysis of 18 U.S. government agencies and private organizations, approximately 80% of U.S. autism research is funded by government sources.<sup>2</sup>

In the U.K., the prevalence of autism is estimated to be 1 in 100 people.<sup>3</sup> The estimated rate is based on a population survey performed by the U.K.’s National Health Service. The prevalence data includes information on the adult prevalence rate, which is the only known prevalence study to have been done of an adult autism population.

Many of the U.K.’s autism research initiatives are spearheaded by [Autistica](#), the UK’s national autism research charity. The organization’s vision is a long, healthy, happy life for autistic people and their families. They fund and promote ground-breaking research, improve understanding of autism and advance new therapies and interventions. The charity has funded the set up and development of some of the most important U.K. studies and scientific assets in autism, including the BASIS and iBASIS trials, the autism-UK family database, and its research network, Discover. Autistica aims to give autistic people and their families a voice in everything they do, from contributing to their Strategy, to making choices on funding calls, to actively running research projects.

In 2017, Autistica launched ‘Discover’ - the first national network for autism research. Discover is driving a step-change in autism research by linking autistic people with institutions carrying out autism research, parents and caregivers, charities, NHS Trusts, hospitals and care

2 Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). 2016 IACC Autism Spectrum Disorder Research Portfolio Analysis Report. January 2019. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <https://iacc.hhs.gov/portfolio-analysis/2016/index.shtml>

3 The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). [Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey](#). Leeds: NHS Information Centre for Health and Social Care

providers. It is encouraging research to focus on what matters most to autistic people and their families. Also, Discover is streamlining the U.K. autism research focus by uniting organizations, coordinating infrastructure, holding a national autism research conference annually, and commissioning research via the network. Discover

is sustaining U.K. autism research by training the next generation of autism research leaders and is increasing links with the community by incentivizing and supporting outreach to local communities and supporting autistic people to undertake research.

## Canada

In Canada, ASD research efforts are largely driven by the government, but are also supported by private organizations, mostly through public-private partnerships. While Canada does not currently have legislation specifically focused on advancing ASD efforts, government agencies are bolstering research efforts related to ASD through chair programs, salary support, research grants and training awards. The Government of Canada also supports surveillance and skill development projects related to ASD.

In Canada, one in 66 children and youth between five and 17 years of age are diagnosed with ASD.<sup>4</sup> The prevalence rate is based on data collected through the Canadian National Autism Spectrum Disorder Surveillance System (NASS). To understand the causes of ASD and to find new treatments, the Government of Canada and several leading private and non-profit organizations are supporting the work of a vibrant research community.

As Canada's health research agency, the **Canadian Institutes of Health Research (CIHR)** is a primary investor in ASD research. CIHR is composed of 13 Institutes and collaborates with partners and researchers to support the discoveries and innovations that improve health and strengthen Canada's health care system. It is an independent agency and is accountable to Parliament through the Minister of Health. Through CIHR's Institute of Neurosciences, Mental Health and Addiction's strategic leadership and collaboration, CIHR advances research

relating to neurosciences, mental health and addictions in Canada. In 2012-13 and 2016-17, CIHR has invested over \$40M in research related to autism. As part of this overall investment, 171 research projects were supported across the country, including six clinical trials spanning a breadth of research areas from behavioral neurosciences and stem cell biology to psychology and education. CIHR also supports the **Kids Brain Health Network** (first trans-Canadian network dedicated to the improvement of assessments, treatments, and scientific knowledge surrounding neurodevelopmental disabilities), and CHILD-BRIGHT. The CHILD-BRIGHT network supports research into new treatments and services for children with brain-based development disabilities, such as autism, so that they can have an improved quality of life.

The Government of Canada supports research professors and their scientific initiatives through the **Canada Research Chairs Program (CRCP)**. In 2012, Health Canada partnered with CIHR, Autism Speaks Canada, the Canadian Autism Spectrum Disorders (ASD) Alliance, Kids Brain Health Network (formerly NeuroDevNet) and the Sinneave Family Foundation to support funding a research professor as a Chair in Autism Spectrum Disorders Treatment and Care Research. This program was specifically created to bridge the significant gap for the translation of research into relevant and efficient treatments and/or standards of care for children and adults with ASD. CIHR is currently supporting three other Chairs (research professors) through the Canada Research

<sup>4</sup> Public Health Agency of Canada. Autism Spectrum Disorder Among Children and Youth in Canada 2018: A report of the National Autism Spectrum Disorder Surveillance System. March 2018. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html>

Chairs program at leading Canadian institutions, focusing on the biology of ASD, developmental neurogenetics, and translational therapeutics. Additionally, a significant portion of CIHR investments in the area of ASD support the Kids Brain Health Network, funded through the federal Networks of Centres of Excellence program. This network is dedicated to understanding the genetic and environmental causes of neurodisabilities, such as ASD.

## Australia

Autism research in Australia is supported by both government funding and private organizations. Australia does not currently have legislative guidance or a national strategy for autism research. However, the government has played an important role in establishing cooperative research programs, national policies on services for persons with disabilities, and universal diagnostic standards.

Prevalence estimates of autism in Australia vary. Government statistics estimate 164,000 Australians had autism in 2015 (Australian Bureau of Statistics [ABS] Survey of Disability, Ageing and Carers), representing an overall prevalence rate of 0.7%, or about 1 in 150 people.<sup>5</sup> However, in a nationally representative sample of children, 1.5 – 2.5% of participant children (approximately 1 in 66 to 1 in 40) were reported to be autistic.<sup>6</sup> Overall, it is likely that the prevalence of autism in Australia is similar to that in other countries included in this analysis.

In 2013, the **Cooperative Research Centre for Living with Autism (Autism CRC)** was established, under the Australian Government's Cooperative Research Centers Program, as the world's first national cooperative research center focused on autism. As a private organization, the Autism CRC receives government funding to assist in achieving the goals of the research center. Autism

Public-private partnerships play a crucial role in ASD research in Canada. Genome Canada, a not-for-profit private organization that is funded by the Government of Canada, has supported ASD research through two large flagship initiatives, the Autism Genome Project and the Autism Spectrum Disorders: Genome to Outcomes Initiative. These initiatives were collaborative and international in scope, and helped identify the genetic risk factors for ASD, charting the path for the development of better diagnosis and personalized care for ASD patients.

CRC takes a whole-of-life approach to autism research, investing in projects across three research programs, "Early Years", "School Years", and "Adulthood". The organization makes a progressive commitment to inclusive research, placing the autistic community at the center of its research efforts. Autism CRC's stated mission is "to motivate, facilitate, and translate collaborative autism research across the lifespan, underpinned by inclusive practices".

In a revolutionary reform to Australian disability support services and funding, the National Disability Insurance Scheme (NDIS) came into effect in 2013 and began its national rollout in July 2016. The NDIS aims to provide all Australians (under the age of 65) who have permanent and significant disabilities with funding for supports and services. It is underpinned by a person-centred model of service delivery in which people with disabilities and their families/carers are involved in the decision-making processes that affect them. This model is designed to allow individuals more choice and control over the design of the supports and services they receive. Autistic Australians are the single largest disability group represented in the NDIS and constitute approximately one third of all NDIS participants.<sup>7</sup>

5 Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *The Medical Journal of Australia*, 202, 317–320; Bent, C. A., Barbaro, J., & Dissanayake, C. (2017). Change in autism diagnoses prior to and following the introduction of DSM-5. *Journal of Autism and Developmental Disorders*, 47, 163–171.  
6 Randall, M., Sciberras, E., Brignell, A., Ihsen, E., Efron, D., Dissanayake, C., & Williams, K. (2016). Autism spectrum disorder: Presentation and prevalence in a nationally representative Australian sample. *Australian and New Zealand Journal of Psychiatry*, 50(3), 243–253. doi:10.1177/0004867415595287  
7 National Disability Insurance Scheme (2019). COAG Disability Reform Council Quarterly Report, 31 March. Available at <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

In 2016, a review of autism diagnostic practices in Australia, jointly commissioned by the Autism CRC and the Commonwealth Department of Social Services, found that diagnostic practices varied considerably between states and territories, especially in regional and remote settings.<sup>8</sup> The review recommended a minimum national standard for autism diagnosis across Australia. In 2018, the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia, supported by the Autism CRC and the National Disability Insurance Agency, was launched.<sup>9</sup> The Guideline promises to provide greater consistency in the diagnostic process for autism across Australia, regardless of location.

Historically, autism research in Australia has been driven by a number of small autism-specific research centers based within universities and other research organizations. Until recently, the bulk of autism research has been funded by two federal government entities: National Health and Medical Research Council (NHMRC), which primarily funds health and medical research; and Australian Research Council (ARC), which provides funding for research across science, the social sciences and the humanities. The establishment of Autism CRC led to a significant increase in Australian investment in autism research, with funding increasing from approximately \$14 million AUD between 2008-2012, to approximately \$44 million AUD between 2013-2017, an increase of 215%.<sup>10</sup> Autism CRC shifted the landscape of autism research in Australia, providing a focused and consistent national approach to autism research and facilitating nation-wide collaboration.

8 Taylor, L., Brown, P., Eapen, V., Harris, A., Maybery, M., Midford, S., ... & Whitehouse, A. (2016). *Autism Spectrum Disorder Diagnosis in Australia. Are we meeting best practice standards?* Brisbane, Australia: Cooperative Research Centre for Living with Autism.

9 Whitehouse, A., Evans, K., Eapen, V. & Wray, J. (2018). *A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia*. Brisbane, Australia: Cooperative Research Centre for Living with Autism.

10 den Houting, J., & Pellicano, E. (2019). A portfolio analysis of autism research funding in Australia, 2008-2017. *Journal of Autism and Developmental Disorders*, advance online publication. doi:10.1007/s10803-019-04155-1

## IACC Strategic Plan Framework

---

To provide a structure for this international portfolio analysis, we used the framework of the U.S.'s *IACC Strategic Plan for ASD*. As previously mentioned, the *IACC Strategic Plan* organizes ASD research around seven research priority areas represented as community-focused “questions.” The questions are divided further into research objectives that address key research needs, gaps, and opportunities identified by the Committee. For the most recent edition, [2016-2017 IACC Strategic Plan for Autism Spectrum Disorder](#), each question in the Strategic Plan includes three to four primary objectives and one cross-cutting objective on the topic of ASD in females. In total, the U.S. monitors progress towards 23 objectives in the 2016-2017 *IACC Strategic Plan*.

Following the development of the *IACC Strategic Plan*, OARC began issuing a series of *IACC ASD Research Portfolio Analysis Reports* to provide the IACC with comprehensive information about the status of autism research funding among federal agencies and private research organizations in the U.S. The reports align data on individual research-related projects with a question and objective in the *IACC Strategic Plan*, providing an accounting of how much funding has supported projects related to *Strategic Plan* objectives and highlighting funding trends. This information has been used to help the IACC in their efforts to monitor ASD research efforts and track progress made each year on the objectives in the *IACC Strategic Plan*. This information also provides guidance to stakeholders as they make funding decisions towards ASD research.

For this report, we will be analyzing international funding trends in alignment with the seven research priority areas or “questions” in the *IACC Strategic Plan*. The seven research questions are represented by the following research priority areas: **Diagnosis & Screening, Biology, Risk Factors, Treatments & Interventions, Services, Lifespan Issues, and Infrastructure & Surveillance (Figure 1)**. This report will not go further to measure international funding towards the *IACC Strategic Plan*'s 23 objectives, as these are research goals that U.S. stakeholders established as priorities for U.S. ASD research. Instead, the purpose of using the existing U.S. *IACC Strategic Plan* structure is to provide a standard framework among the four countries to compare and analyze investments among different ASD research areas. Project information will therefore only be assessed at the research topic level.

| <i>IACC Strategic Plan</i><br>Research Priority Areas                               |                                          |
|-------------------------------------------------------------------------------------|------------------------------------------|
|    | <b>SCREENING &amp; DIAGNOSIS</b>         |
|    | <b>BIOLOGY</b>                           |
|    | <b>RISK FACTORS</b>                      |
|   | <b>TREATMENTS &amp; INTERVENTIONS</b>    |
|  | <b>SERVICES</b>                          |
|  | <b>LIFESPAN ISSUES</b>                   |
|  | <b>INFRASTRUCTURE &amp; SURVEILLANCE</b> |

**Figure 1.** The research priority areas of the 2016-2017 *IACC Strategic Plan for ASD Research* are represented by the icons to the left of each question.



# ASD Research Funding and Funders in 2016

# 2016 ASD Research Funding

Australia, Canada, U.K., and the U.S. requested 2016 autism-related research project and funding information from public body entities and private organizations, including the annual budget for each project and its relevance to the seven research priority areas. Details describing the data collection methods and currency conversion for each country are included in **Appendix B**.

Australia, Canada, the U.K., and the U.S. invested a total amount of \$395.9 million in ASD research funding in 2016, distributed among 1,552 projects (**Table 1**). The U.S. had the largest funding total with \$364.4 million and 1,360

projects. The U.K. funded \$14.8 million in ASD research and had 59 projects. Canada invested nearly \$11 million in ASD research and 74 projects. Lastly, Australia funded 59 projects that amounted to almost \$6 million in autism research. For the U.K. and Australia, research projects receive all the designated funds for a project in the first year of the project. For these two countries, projects that started research activity prior to 2016 but are still ongoing will not contribute any funding to the 2016 portfolio, but these projects are still accounted for in each country's project count.

| 2016<br>ASD Research Total Funding and Project Counts by Country |                                                                 |                                                      |
|------------------------------------------------------------------|-----------------------------------------------------------------|------------------------------------------------------|
| Country                                                          | Funding Amount in U.S. Dollars<br>(Percentage of total funding) | Project Count<br>(Percentage of total project count) |
| United States                                                    | \$364,435,254 (92%)                                             | 1,360 (88%)                                          |
| United Kingdom                                                   | \$14,848,929 (4%)                                               | 59 (4%)                                              |
| Canada                                                           | \$10,719,396 (3%)                                               | 74 (5%)                                              |
| Australia                                                        | \$5,854,451 (1%)                                                | 59 (4%)                                              |
| Grand Total                                                      | \$395,858,120                                                   | 1,552                                                |

**Table 1.** In 2016, there were 1,552 ASD research projects totaling \$395.8 million among Australia, Canada, the United Kingdom, and the United States. Currency conversion methods are described in **Appendix B**.

## 2016 ASD Research Funders in Each Country

Among the four countries, there were 34 funders included in the 2016 analysis. Australia included funding information from two federal government research councils and three private entities. Canada collected funding information from one government agency and two not-for-profit private organizations. The U.K. provided funding information from five public body agencies, which are non-departmental research councils, as well as three private organizations. The U.S. collected data from nine federal government agencies and nine private

organizations. These 34 agencies and organizations are listed in **Table 2**. Each country collected from the major private and public ASD-related funders in their respective countries, however some funders may not have been identified for this analysis. Future iterations of this report intend to include more funders from each country as well as more countries. Brief summaries of the mission areas for each agency and organization that contributed to the analysis can be found in **Appendix C** of this report.

| Australia                                            |                                                                 |
|------------------------------------------------------|-----------------------------------------------------------------|
| Government Agencies                                  | Private Organizations                                           |
| Australian Research Council (ARC)                    | Financial Markets Foundation for Children                       |
| National Health and Medical Research Council (NHMRC) | Ian Potter Foundation                                           |
|                                                      | Cooperative Research Centre for Living with Autism (Autism CRC) |

| Canada                                        |                               |
|-----------------------------------------------|-------------------------------|
| Government Agencies                           | Private Organizations         |
| Canadian Institutes of Health Research (CIHR) | Brain Canada Foundation (BCF) |
|                                               | Ontario Brain Institute (OBI) |

| United Kingdom                                             |                       |
|------------------------------------------------------------|-----------------------|
| Public Body Agencies                                       | Private Organizations |
| Economic and Social Research Council (ERSC)                | Autistica             |
| Engineering and Physical Sciences Research Council (EPSRC) | British Academy       |
| Innovate UK                                                | Wellcome Trust        |
| Medical Research Council (MRC)                             |                       |
| National Institute for Health Research (NIHR)              |                       |

| United States                                       |                                                      |
|-----------------------------------------------------|------------------------------------------------------|
| Government Agencies                                 | Private Organizations                                |
| Administration for Community Living (ACL)           | Autism Research Institute (ARI)                      |
| Agency for Healthcare Research and Quality (AHRQ)   | Autism Science Foundation (ASF)                      |
| Centers for Disease Control and Prevention (CDC)    | Autism Speaks (AS)                                   |
| Department of Defense – Army (DoD – Army)           | Brain & Behavior Research Foundation (BBRF)          |
| Department of Education (ED)                        | Center for Autism and Related Disorders (CARD)       |
| Environmental Protection Agency (EPA)               | New England Center for Children (NECC)               |
| Health Resources and Services Administration (HRSA) | Organization for Autism Research (OAR)               |
| National Institutes of Health (NIH)                 | Patient-Centered Outcomes Research Institute (PCORI) |
| National Science Foundation (NSF)                   | Simons Foundation (SF)                               |

**Table 2.** ASD research project information was collected from 34 public and private entities among Australia, Canada, U.K., and the U.S. for the 2016 *International ASD Research Portfolio Analysis Report*.

## ASD Research Funding Provided by Each Funder in 2016

### Australia

Australia contributed \$5,854,541 across 59 autism research projects in 2016 (**Table 3**). There were two Australian government research councils and three private organizations included in the analysis. Two organizations contributed 98% of Australia's autism research investment in 2016. The Autism CRC, a private organization, was the largest funder with \$3.2 million in investment across 37 autism research projects. The other major funder was a

government research council, the NHMRC, reporting more than \$2.5 million and 16 research projects. The second government council, the ARC, did not contribute any new funding in 2016 but had ongoing projects included in Australia's portfolio. The Financial Markets Foundation for Children and the Ian Potter Foundation, two non-profit organizations, each funded one project in 2016.

| Australia's 2016 ASD Research Funding by Agency/Organization    |                    |               |
|-----------------------------------------------------------------|--------------------|---------------|
| Funding Agency/Organization                                     | 2016 Funding (USD) | Project Count |
| Cooperative Research Centre for Living with Autism (Autism CRC) | \$3,173,265        | 37            |
| National Health and Medical Research Council (NHMRC)            | \$2,557,017        | 16            |
| Financial Markets Foundation for Children                       | \$109,860          | 1             |
| Ian Potter Foundation                                           | \$14,400           | 1             |
| Australian Research Council (ARC)                               | \$0                | 4             |
| <b>Total</b>                                                    | <b>\$5,854,541</b> | <b>59</b>     |

**Table 3.** The table lists the total funding and number of projects provided by the five Australian funders included in the analysis.

# Canada

In 2016, Canada supported 74 ASD research projects totaling \$10,719,396 (Table 4). Research project data were collected from two private organizations and one Canadian government agency. The government agency, the Canadian Institutes of Health Research (CIHR), was the largest funder with nearly \$7 million in ASD research and 61

projects. The second largest contributor was the Brain Canada Foundation (BCF), which is a private organization that reported \$2.6 million for 11 projects. The private organization of the Ontario Brain Institute (OBI) funded two projects that covered almost \$1.2 million in funding.

| Canada's 2016 ASD Research Funding by Agency/Organization |                    |               |
|-----------------------------------------------------------|--------------------|---------------|
| Funding Agency/Organization                               | 2016 Funding (USD) | Project Count |
| Canadian Institutes of Health Research (CIHR)             | \$6,974,431        | 61            |
| Brain Canada Foundation (BCF)                             | \$2,584,273*       | 11            |
| Ontario Brain Institute (OBI)                             | \$1,160,693**      | 2             |
| Total                                                     | \$10,719,396       | 74            |

**Table 4.** Total funding and number of projects towards ASD research provided by the three Canadian funders.

\* Funding provided by BCF includes co-funded ASD research projects. While BCF leads the ASD research projects provided in this report, they are not the sole funders and included funding from private donors and organizations in their total amount. BCF's funding numbers are not duplicative of any agency/organization included in this report.

\*\* The annual funding amount for some projects reported by OBI are prorated estimates for the autism-related portion of a larger project.

## United Kingdom

The U.K. provided funding information from five public body agencies as well as three private organizations. Overall, the U.K. contributed \$14,848,929 towards autism research and had 59 projects (**Table 5**). The largest funder of autism research was the private organization, Wellcome Trust, which provided \$4.2 million in autism research

among 12 projects. Three public body agencies followed, the Medical Research Council (\$3.3 million, 7 projects), the Economic and Social Research Council (\$3.1 million, 11 projects), and the National Institute for Health Research (\$2.8 million, 9 projects).

| United Kingdom's 2016 Autism Research Funding by Agency/Organization |                     |               |
|----------------------------------------------------------------------|---------------------|---------------|
| Funding Agency/Organization                                          | 2016 Funding (USD)  | Project Count |
| Wellcome Trust                                                       | \$4,200,832         | 12            |
| Medical Research Council (MRC)                                       | \$3,268,036         | 7             |
| Economic and Social Research Council (ESRC)                          | \$3,127,812         | 11            |
| National Institute for Health Research (NIHR)                        | \$2,763,124         | 9             |
| Engineering and Physical Sciences Research Council (EPSRC)           | \$1,133,952         | 4             |
| Autistica                                                            | \$355,174           | 14            |
| British Academy                                                      | \$0                 | 1             |
| Innovate UK                                                          | \$0                 | 1             |
| <b>Total</b>                                                         | <b>\$14,848,929</b> | <b>59</b>     |

**Table 5.** The list of agencies and private organizations that contributed to the United Kingdom's 2016 autism research portfolio.

## United States

The 18 agencies and organizations that participated in the U.S. supported 1,360 ASD research projects totaling \$364,435,254 (**Table 6**). The National Institutes of Health (NIH) was the leading federal (and overall) contributor of funding for ASD research in 2016 with a total of \$234.4 million, funding 547 projects. The next largest federal

funder was the Department of Education, with \$19.6 million, followed by the Centers for Disease Control and Prevention (CDC), with \$15.4 million. As in previous years, the Simons Foundation and Autism Speaks were the largest private funders of ASD research, with investments of \$61.8 million and \$6.7 million, respectively.

## United States' 2016 ASD Research Funding by Agency/Organization

| Funding Agency/Organization                          | 2016 Funding (USD)   | Project Count |
|------------------------------------------------------|----------------------|---------------|
| National Institutes of Health (NIH)                  | \$234,392,406        | 547*          |
| Simons Foundation (SF)                               | \$61,754,800         | 283           |
| Department of Education (ED)                         | \$19,627,374         | 75            |
| Centers for Disease Control and Prevention (CDC)     | \$15,390,203         | 28            |
| Health Resources and Services Administration (HRSA)  | \$8,576,199**        | 30            |
| Department of Defense - Army (DoD-Army)              | \$6,888,542          | 58            |
| Autism Speaks (AS)                                   | \$6,745,989          | 90            |
| National Science Foundation (NSF)                    | \$4,488,826          | 44            |
| Administration for Community Living (ACL)            | \$1,798,164          | 7             |
| Brain & Behavior Research Foundation (BBRF)          | \$1,688,387          | 56            |
| Patient-Centered Outcomes Research Institute (PCORI) | \$539,719            | 7             |
| Center for Autism and Related Disorders (CARD)       | \$690,000            | 9             |
| Autism Science Foundation (ASF)                      | \$474,072            | 30            |
| Environmental Protection Agency (EPA)                | \$420,364            | 1             |
| Autism Research Institute (ARI)                      | \$347,650            | 8             |
| New England Center for Children (NECC)               | \$259,060            | 64            |
| Organization for Autism Research (OAR)               | \$199,803            | 19            |
| Agency for Healthcare Research and Quality (AHRQ)    | \$153,695            | 4             |
| <b>Total</b>                                         | <b>\$364,435,254</b> | <b>1,360</b>  |

**Table 6.** The table lists the total funding and number of projects provided by the 18 federal agencies and private organizations included for 2016. Together, the agencies and organizations funded 1,360 projects, representing an overall investment of \$364,435,254.

\*The NIH project number shown reflects unique NIH projects. Portions of a project funded by more than one NIH institute ("co-funds") were combined and only counted as a single project. This approach differs from that used in the NIH RePORT database, where each co-fund portion is counted as a separate project.

\*\*The annual funding amount for some projects reported by HRSA are prorated estimates for the autism-related portion of a larger project.

# Institutions Receiving Research Funding in Each Country

For the four countries included in this analysis, the major recipients of ASD research funding tended to be academic research institutions. In Australia, four institutions were universities that support researchers and students in their autism research endeavors, and one organization was a service provider with a strong research focus. While Canada and the U.K. included academic establishments among their highest funded institutions, each also included several hospitals. In Canada and the U.K., clinical academics often have dual roles across hospitals and

universities. Within the U.S., four of the five institutions that received the most funding in 2016 were universities that support academic researchers and research programs in medicine, behavioral health, services research, and other disciplines. NIH’s intramural research program, the internal research program at NIH, received a significant portion of U.S. funding for ASD research. The following tables provide additional information about the institutions that had the highest funding in 2016 for each country (Tables 7-10).

| Which Australian institutions had the highest levels of autism research funding in 2016? |               |               |
|------------------------------------------------------------------------------------------|---------------|---------------|
| Institution                                                                              | Funding (USD) | Project Count |
| University of Melbourne                                                                  | \$1,923,030   | 6             |
| University of Queensland                                                                 | \$1,426,200   | 10            |
| Curtin University                                                                        | \$589,959     | 4             |
| Autism Spectrum Australia (Aspect)                                                       | \$427,319     | 1             |
| La Trobe University                                                                      | \$391,756     | 3             |

**Table 7.** Institutions in Australia with the most autism-related research funding from government and private sources in 2016.

### Which Canadian institutions had the highest levels of autism research funding in 2016?

| Institution                                    | Funding (USD) | Project Count |
|------------------------------------------------|---------------|---------------|
| Hospital for Sick Children                     | \$1,625,296   | 8             |
| McGill University                              | \$1,324,452   | 11            |
| University of British Columbia                 | \$1,269,207   | 7             |
| Holland Bloorview Kids Rehabilitation Hospital | \$1,268,520   | 4             |
| Centre for Addiction and Mental Health         | \$990,548     | 2             |

**Table 8.** Institutions in Canada with the most ASD-related research funding from government and private sources in 2016.

### Which U.K. institutions had the highest levels of autism research funding in 2016?

| Institution                                                  | Funding (USD) | Project Count |
|--------------------------------------------------------------|---------------|---------------|
| University of Edinburgh                                      | \$5,569,179   | 2             |
| Central Manchester University Hospitals NHS Foundation Trust | \$2,421,382   | 1             |
| King's College London                                        | \$1,668,839   | 11            |
| University of York                                           | \$1,450,930   | 2             |
| Heriot-Watt University                                       | \$1,013,907   | 1             |

**Table 9.** Institutions in the U.K. with the most autism-related research funding from government and private sources in 2016.

## Which U.S. institutions had the highest levels of autism funding in 2016?

| Institution                                                 | Funding (USD) | Project Count |
|-------------------------------------------------------------|---------------|---------------|
| University of California, Davis                             | \$18,355,969  | 54            |
| Yale University                                             | \$15,308,925  | 41            |
| University of California, Los Angeles                       | \$15,010,953  | 44            |
| National Institutes of Health - Intramural Research Program | \$13,085,768  | 12            |
| University of North Carolina at Chapel Hill                 | \$10,481,404  | 34            |

**Table 10.** Institutions within the U.S. with the most ASD-related research funding from government and private sources in 2016.

# Analysis of ASD Research Priority Areas in 2016

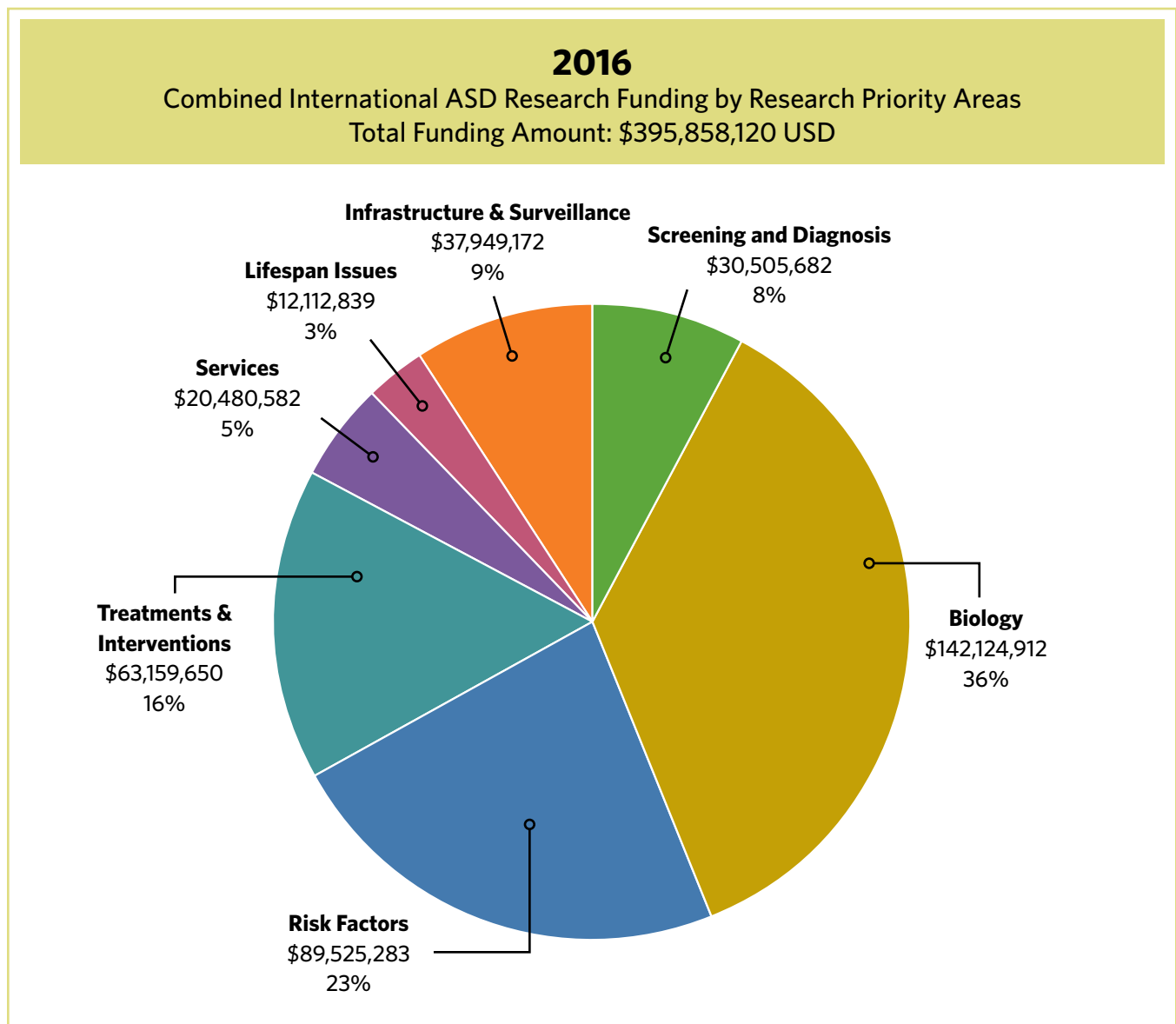
## ASD Research Priority Areas Funded in 2016

Using the *IACC Strategic Plan* framework, projects were aligned with the seven research priority areas to better understand what areas of research were funded in 2016.

**Figure 2** illustrates the breakdown of the combined research funding from the four countries across the seven research priority areas: **Screening and Diagnosis, Biology,**

**Risk Factors, Treatments and Interventions, Services,** **Lifespan Issues,** and **Infrastructure and Surveillance.**

Identifying how current research investments correspond to the research areas provides an understanding of which areas are well-supported versus those that may need additional attention or development.



**Figure 2.** The combined total investment from the four countries in the seven research priority areas.

International ASD research funding in 2016 supported projects relevant to all seven research priority areas. Described below is the combined investment from all four countries towards each of the seven research areas:

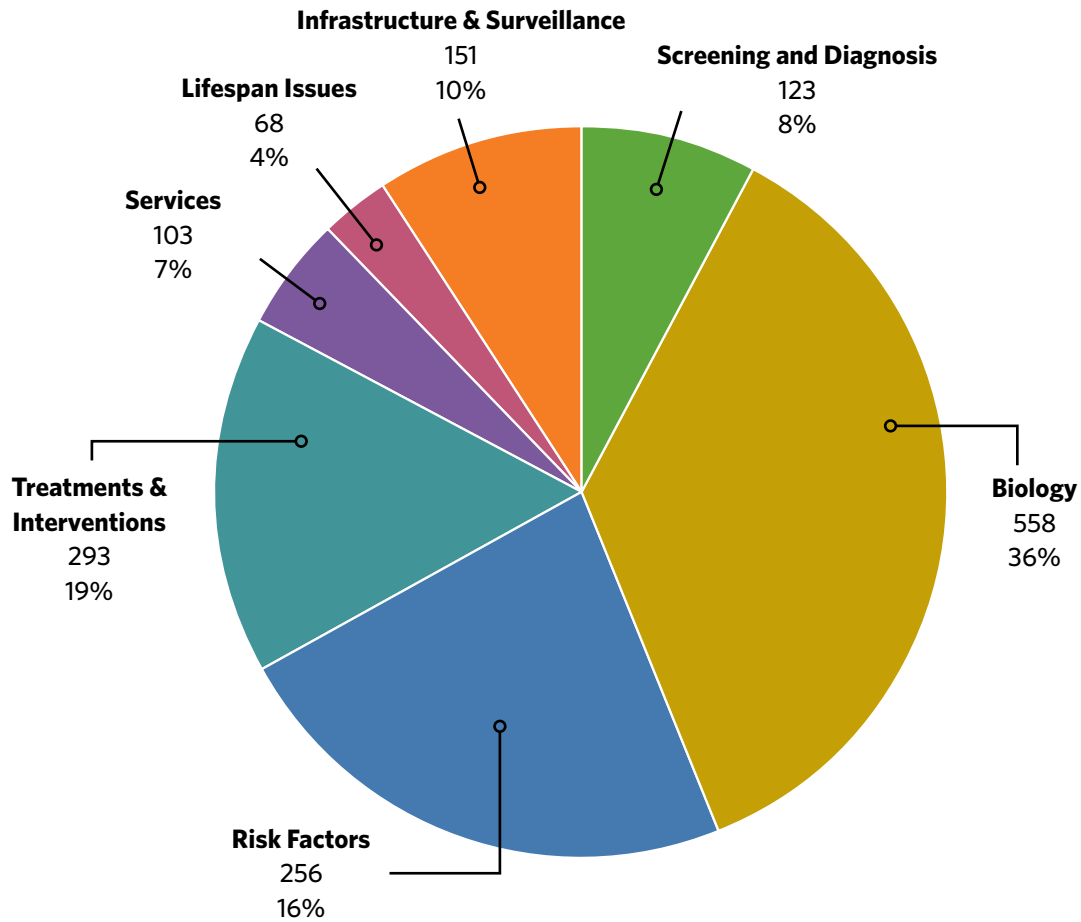
- **Biology of ASD:** The largest portion of funding addressed the underlying biology of ASD (36%). Projects assigned to this research area seek to understand the biological differences and mechanisms in early development and throughout life that contribute to ASD symptoms, as well as the characterization of the behavioral and cognitive aspects of ASD.
- **Risk Factors:** This was the second largest funded research area (23%); research in this priority area aims to identify potential causes and risk factors for ASD. Projects associated with risk factors explore the role of genetics, epigenetics, and the environment in the development of ASD, as well as the interactions between risk factors.
- **Treatments and Interventions:** Research into treatments and interventions for ASD, including behavioral therapies, pharmacological treatments, and technology-based interventions, followed with 16% of total funding in 2016.
- **Infrastructure and Surveillance:** Investment in infrastructure and surveillance was 9% of overall funding. Projects included in infrastructure and surveillance cover research infrastructure, data sharing, ASD surveillance, and the communication/dissemination of research findings and evidence-based practices. There is also a focus on increasing participation in the collection of biospecimens as well as developing the professional workforce that conducts research and provides services to individuals with autism and their families.

- **Screening and Diagnosis:** Research to improve screening and diagnosis of ASD was 8% of research funding in 2016. Projects included within screening and diagnosis comprise research to develop and improve biomarkers, screening tools, and diagnostic instruments to aid in early identification.
- **Services:** This area, which focuses on funding research to improve services and supports for people with ASD, received 5% of ASD research funding.
- **Lifespan Issues:** This area had the least amount of funding (3%); research in lifespan issues identifies and addresses the needs of youth with ASD transitioning to adulthood as well as quality of life factors throughout the lifespan.

When the number of projects that align with each research area is considered, as opposed to the total funding for these projects, the distribution is slightly different due to differences in the relative sizes of projects falling under each of the seven research categories as well as each country's funding mechanisms. In 2016, there were 1,552 projects total. The percentage of total projects aligned with each research area were as follows: **Screening and Diagnosis**, 8%; **Biology**, 36%; **Risk Factors**, 16%; **Treatments and Interventions**, 19%; **Services**, 7%; **Lifespan Issues**, 4%; **Infrastructure and Surveillance**, 10% (Figure 3).

**2016**

Combined International ASD Research Funding by Research Priority Areas  
Total Project Count: 1,552



**Figure 3.** The combined 2016 projects provided by Australia, Canada, U.K., and the U.S. aligned to the seven research areas.

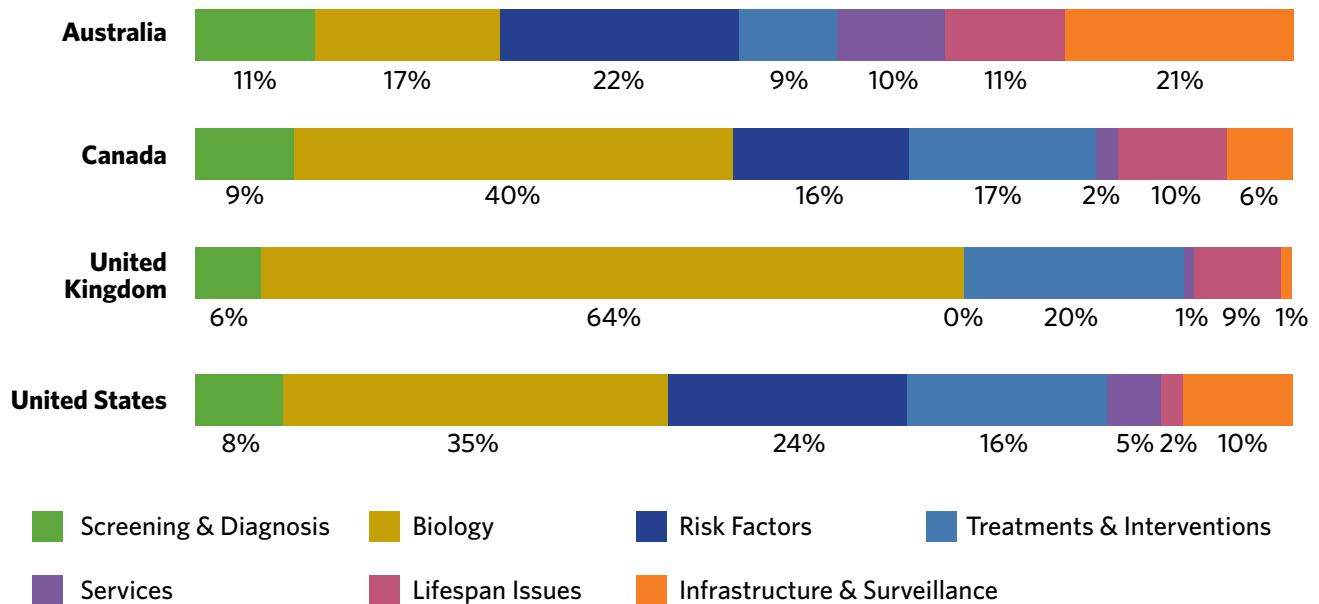
## Comparative Analysis of Each Country's ASD Research Portfolio by Research Priority Areas

Due to the significant differences in funding and project counts among the four countries, comparing funding towards the seven research priority areas by dollar amounts would provide minimal information on research trends across the four countries. A more useful comparative analysis would be to assess the proportion of each country's portfolio towards the seven research priority areas. **Figure 4** displays the differences and similarities in funding priorities among Australia, Canada, United Kingdom, and the United States. Some of the notable trends include:

- **Screening and Diagnosis:** Each of the four countries has similar proportions in funding in screening and diagnosis, with nearly a tenth of each country's funding going towards this research area.
- **Biology of ASD:** For the U.K., U.S., and Canada, biology was the greatest area of investment. For Australia, biology received a significant investment, although it was not its most well-funded research area.
- **Risk Factors:** Research into identifying risk factors was the largest funded area in Australia, the second largest funded area in the U.S. and the third largest funded area in Canada. The U.K. did not fund research for risk factors in 2016.
- **Treatments and Interventions:** Across all four countries, treatments and interventions saw considerable portions of funding.
- **Services:** Services research had varying degrees of investment. Australia had the largest proportion of investment in services research among the four countries. For the U.K. and Canada, it was the least funded area of research.
- **Lifespan Issues:** Research on lifespan issues received a similar proportion of funding in Australia, Canada, and the U.K., whereas it was the least funded area of research in the U.S.
- **Infrastructure and Surveillance:** There were also differences in infrastructure and surveillance investment among the four countries. It was the second largest funded area in Australia and had a significant portion of funding in the U.S., however it was a small portion of funding for Canada and the U.K. in 2016.

## 2016

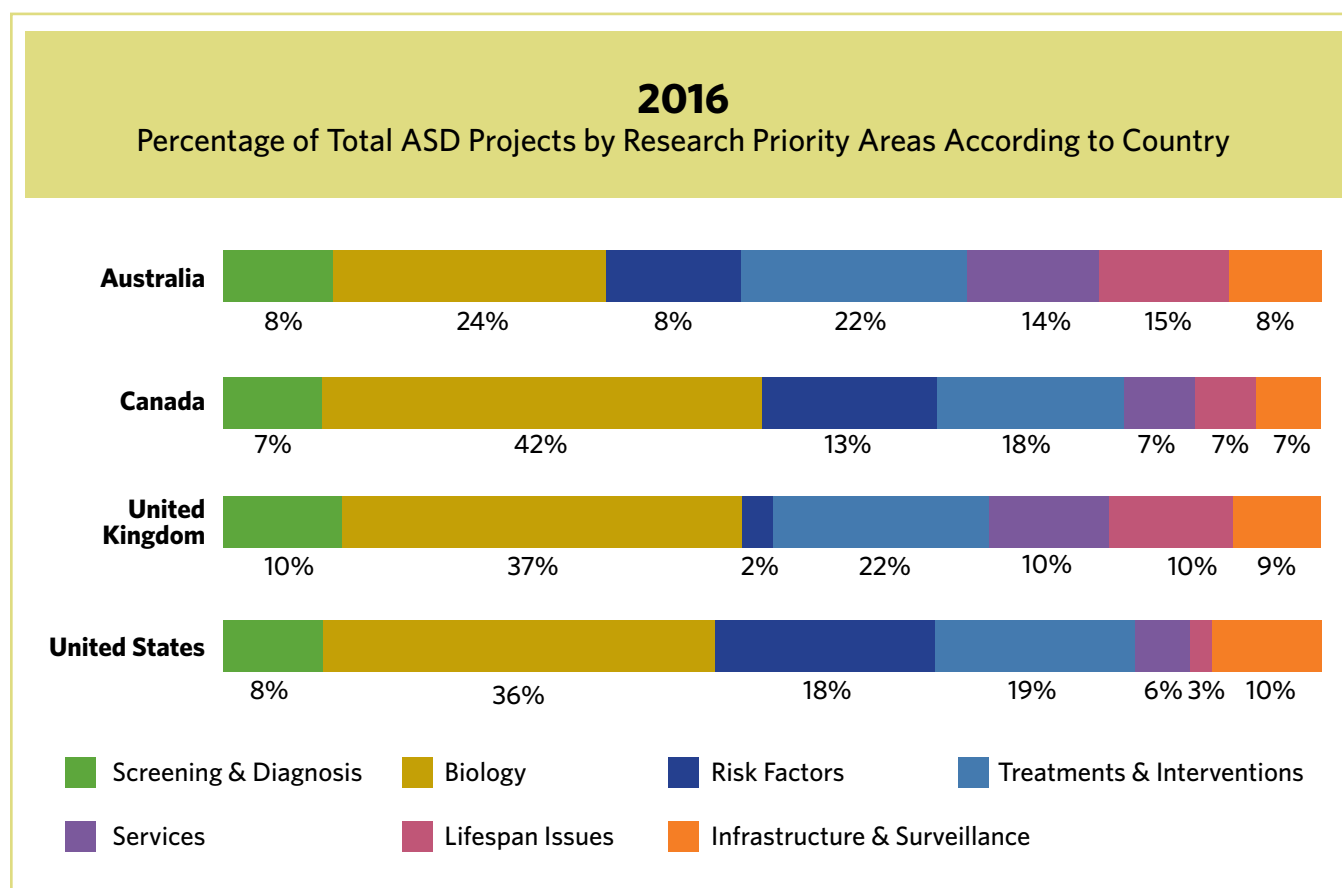
### Percentage of Total ASD Funding by Research Priority Areas According to Country



**Figure 4.** The percentage of ASD funding by research priority areas for Australia, Canada, United Kingdom, and the United States. Due to rounding, the percentages for each country may not add to 100 and research priority areas with less than 1% have been rounded up to 1%.

While the funding information provides an idea of each country's interests in ASD research, it is equally important to look at the proportions of each country's project counts towards the research priority areas (**Figure 5**). Due to differences in funding mechanisms among the countries and the amount of funding needed for different areas of research, the proportion of ASD projects by research priority area displays a different perspective than the funding percentages for each country. Highlights among the seven research priority areas are listed below:

- Biology of ASD:** Across the four countries, biology had the largest proportions of research projects.
- Treatments & Interventions:** Research on treatments and interventions had the second largest proportion of projects among the four countries.
- Risk Factors:** Research on ASD risk factors was a prominent research area for the U.S. and Canada portfolios, while it was a slightly smaller portion of Australia's portfolio. Risk factors had the smallest percentage of projects for the U.K. However, the U.K. did not have any funding associated with risk factors in 2016, therefore this shows there is ongoing research on risk factors in the U.K.



**Figure 5.** The percentage of total ASD projects for each country by research priority areas. Due to rounding, the percentages for each country may not add to 100.

- **Screening and Diagnosis:** Research on screening and diagnosis had similar proportions of projects among the four countries, with nearly a tenth of each country's project count.
- **Services:** When comparing the proportions of projects assigned to services, Australia had the largest percentage designated to services research. The U.S. had the smallest proportion of projects associated with services research among the four countries.
- **Lifespan Issues:** The percentage of project counts for research in lifespan issues followed similar patterns to the funding proportions; Australia, Canada, and the U.K. had a larger number of projects assigned to lifespan research than the U.S.

- **Infrastructure and Surveillance:** The four countries had similar proportions of projects in infrastructure and surveillance. Each country had nearly a tenth of projects assigned to infrastructure and surveillance.

For a more in-depth analysis of each country's portfolio, the following sections in this report will provide an overview of progress in 2016 on each country's investments in ASD research as well as details about specific initiatives.

## Australia's 2016 Autism Research Portfolio

Australia invested in autism research projects that aligned with all seven of the research priority areas in 2016 (**Figure 7**). Differing from the other three countries, the largest proportion of funding went towards investments in **Risk Factors** (22%), closely followed by **Infrastructure and Surveillance** (21%). The next largest funded area supported understanding the underlying **Biology** of ASD (17%). The remaining four priority areas received similar investment: **Lifespan Issues** and **Screening and Diagnosis** each received 11% of Australia's total funding, **Services** received 10%, and **Treatments and Interventions** received 9%.

Assessing Australia's portfolio, project counts assigned to each research priority area varied compared to the funding patterns (**Table 12**). Similar to the U.K. portfolio, it is important to review the project counts for each research priority area as Australia funds their projects in the first year of research only. The largest proportion of research projects were assigned to **Biology** (14 projects). This was followed by 13 projects in **Treatments and Interventions**, 9 projects in **Lifespan Issues**, and 8 projects in **Services** research. The final three research areas each had 5 projects in 2016: **Screening and Diagnosis**, **Risk Factors**, and **Infrastructure and Surveillance**.

Australia's portfolio was more evenly distributed across the seven research priority areas than the other countries included in the analysis. A previous portfolio analysis of 2008 - 2017 funding indicates that this even distribution has been a consistent feature of Australian investment in autism research since 2013.<sup>11</sup> Australia's autism research (\$5.9 million) is relatively small in comparison to the other countries. As a result, Australia's funding and project count both provide important data. Since research funding is awarded in the first year of the project, it is important to note that the profile of funding in a given year may be

affected by any particularly large grants allocated in that year. For example, during the 2016 period, **Risk Factors** and **Infrastructure and Surveillance** were the most-funded research priority areas in Australia; however, both priority areas received single grants valued at more than \$1 million in 2016. During the same period, these priority areas had the lowest project counts.

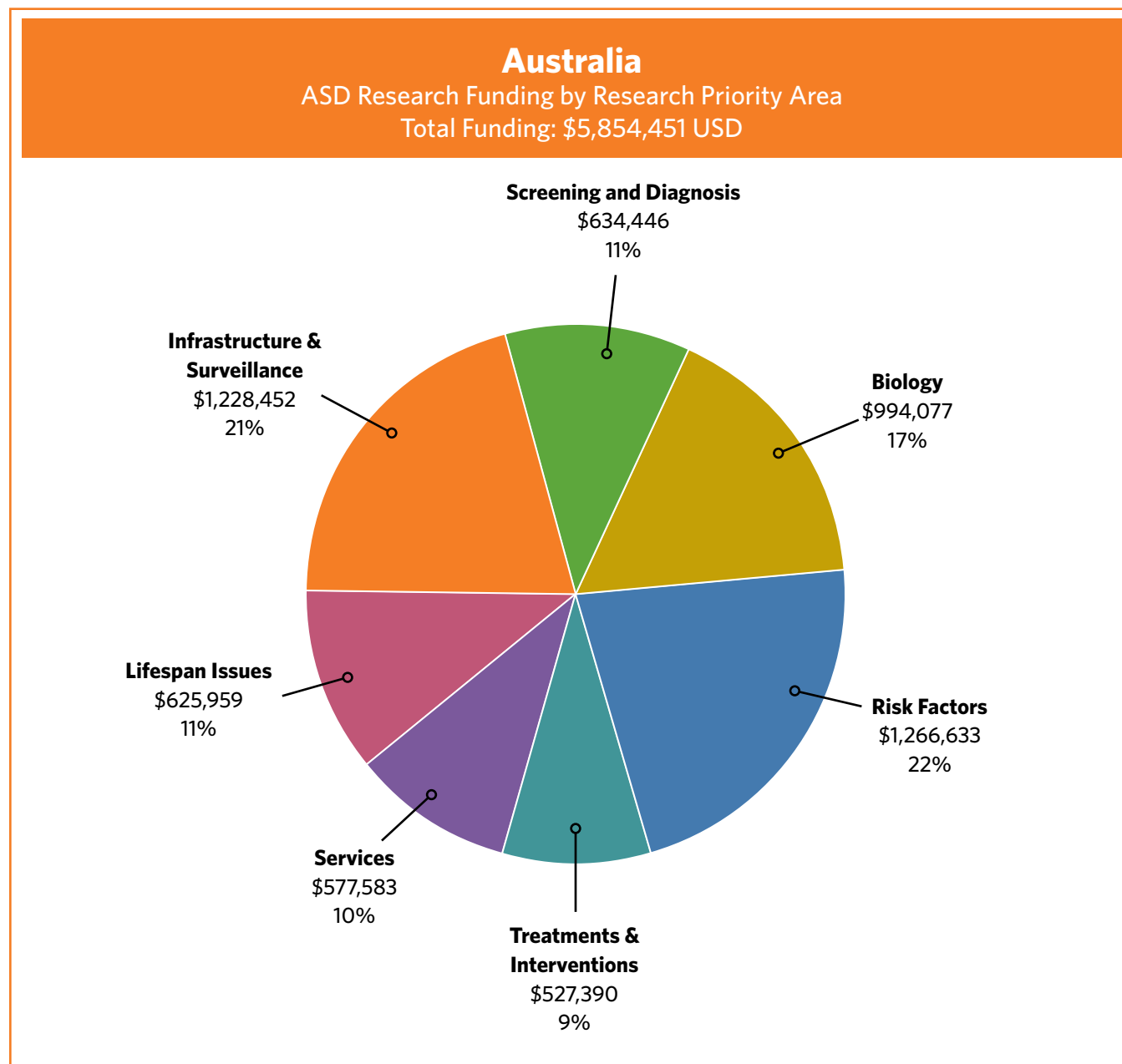
Autism research in Australia underwent a transformation in 2013, with the establishment of the Autism CRC, a government-funded Cooperative Research Centre. The Autism CRC is a progressive research organization, with a focus on the empowerment of autistic people and a commitment to inclusive and participatory research practice. Autism CRC deliberately invests in research across the lifespan, with three programs of research: Early Years, School Years, and Adulthood. Across these three programs, Autism CRC has invested in more than 60 research projects across its six years of operation.

Of particular note, within the Early Years program, Autism CRC invested in the creation of the Australian Autism Biobank, a repository of biological and phenotypic data from almost 3,000 participants. Data from the biobank will be used to inform research supporting earlier and more accurate autism diagnosis. In 2016, the Autism CRC invested \$1.2 million (\$1.7 million AUD) in infrastructure to support the Australian Autism Biobank. Within the School Years and Adult Years programs, Autism CRC invested in three longitudinal studies: a study of children on the spectrum aged 4 - 15, a study of autistic school-leavers aged 15 to 25, and a study of autistic adults aged 25 and over. Together, these longitudinal studies will provide a comprehensive profile of autistic Australians across the lifespan, contributing to understanding of autistic developmental trajectories and outcomes.

<sup>11</sup> den Houting, J., & Pellicano, E. (2019). A portfolio analysis of autism research funding in Australia, 2008-2017. *Journal of Autism and Developmental Disorders*, advance online publication. doi:10.1007/s10803-019-04155-1

The other major organization funding autism research in Australia is the National Health and Medical Research Council (NHMRC). The NHMRC is Australia's leading health and medical research funding body, and consistent with this remit, their investments in autism research primarily fund research targeting Biology and Risk Factors.

For example, of the six autism research projects funded by the NHMRC in 2016, five focused on either Biology or Risk Factors, including one large grant of over \$1.2 million (\$1.7 million AUD) to a project focusing on autism genetic discovery.



**Figure 6.** Australia's 2016 autism research portfolio represented by the seven research topic areas. Due to rounding, the percentages for each country may not add to 100.

| Australia                     |                   |
|-------------------------------|-------------------|
| Autism Research Priority Area | Project Count (%) |
| Screening & Diagnosis         | 5 (8%)            |
| Biology                       | 14 (24%)          |
| Risk Factors                  | 5 (8%)            |
| Treatments & Interventions    | 13 (22%)          |
| Services                      | 8 (14%)           |
| Lifespan Issues               | 9 (15%)           |
| Infrastructure & Surveillance | 5 (8%)            |
| <b>Total</b>                  | <b>59</b>         |

**Table 11.** Australia's 2016 projects aligned to the research topic areas.

## Canada's 2016 Autism Research Portfolio

In 2016, Canada supported research projects towards all seven of the ASD research priority areas (**Figure 7**). The largest amount of funding went towards understanding the underlying **Biology** of ASD (40%). Research funding towards developing and improving ASD **Treatments and Interventions** received 17% of Canada's total funding and it was followed closely by funding towards studying **Risk Factors** for ASD (16%). The next most highly-funded research areas were **Lifespan Issues**, which received 10% of funding, and **Screening and Diagnosis**, which was 9% of Canada's ASD portfolio. The last two areas of research funding were **Infrastructure and Surveillance** (6%) and **Services** (2%).

When viewing Canada's projects assigned to each research priority area there is a similar trend to the funding patterns (**Table 12**). **Biology** had the largest portion of research projects assigned to a priority area (31 projects). It was followed by 13 projects in **Treatments and Interventions** and 10 projects towards research to discover **Risk Factors**. The last four research areas each had 5 projects in 2016: **Screening and Diagnosis**, **Services**, **Lifespan Issues**, **Infrastructure and Surveillance**.

The Kids Brain Health Network (KBHN), a public-private partnership that includes support from CIHR, is the leading pan-Canadian research network dedicated to understanding the genetic and environmental causes of neurodevelopmental disorders, focusing on ASD, cerebral palsy and fetal alcohol spectrum disorders. The KBHN represents a total federal investment of \$39 million CAD, including \$9.3 million CAD from CIHR. ASD researchers from the network come from multiple scientific disciplines and collaborate with community, industry, government and non-profit stakeholders to understand the genetic and environmental causes of autism. KBHN's focus on ASD research spans four broad topics and areas of

strategic importance: Genomic and epigenetic influences on development and symptoms of ASD, Early Detection Research, Social Communication and Resiliency, Youth Perspectives. Each of these topics have research efforts focused on all seven of the IACC ASD research priority areas.

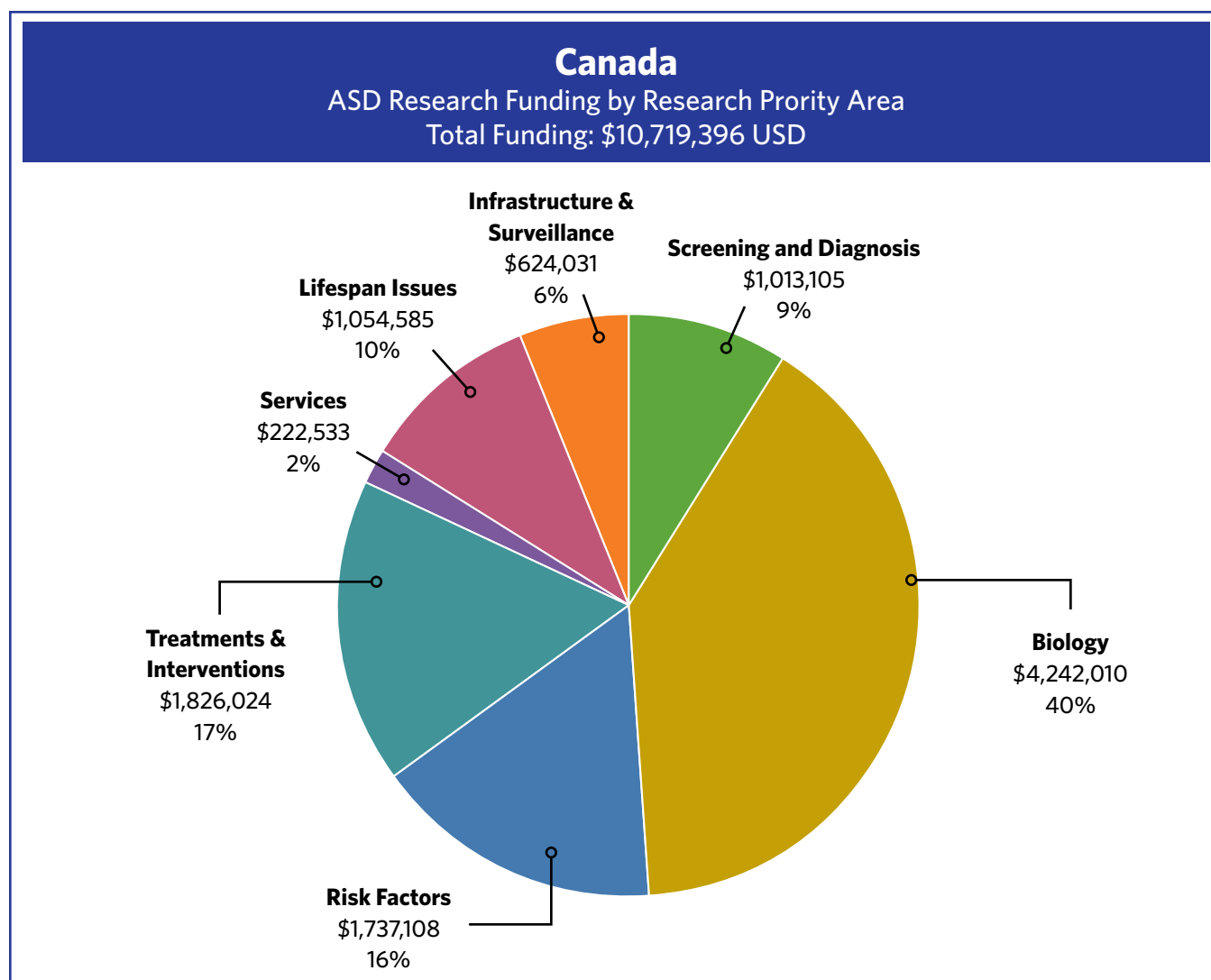
ASD researchers affiliated with the network recently developed the Social ABCs early behavioral intervention program – a 12-week evidence-based intervention for ASD targeting toddlers (18-30 months) with confirmed or suspected ASD. It teaches parents how to help toddlers vocalize in more meaningful ways. KBHN turned it into a train-the-teacher program for early childhood educators (ECEs), demonstrating that Social ABC's is an accessible, less resource-intensive and less costly option for parents to assist their child in developing communication skills, without having to wait for a formal ASD diagnosis. Researchers from the KBHN continue to improve the effectiveness of the program.

The non-profit organization, the Ontario Brain Institute (OBI), supports the Province of Ontario Neurodevelopmental Disorders (POND) research network, which is investigating the biology underlying neurodevelopmental disorders, including ASD, to create new opportunities for improved care and long-term outcomes for children. Funding included in this analysis reflects children recruited with a primary diagnosis of ASD. The goal of the network is to understand the biological mechanisms underlying these disorders and subgroup individuals based on biology rather than diagnostic label, which may result in more targeted treatments. While POND projects were aligned with the biology research area, it is important to note that the research being conducted within the network encompasses biology, risk factors, and treatment research.

The Brain Canada Foundation (BCF) supported research in 2016 across screening and diagnosis, biology, risk factors, and treatments and interventions. The non-profit organization focuses on understanding the brain and its role in diagnosis and treatment of disorders of the brain. In 2016, the BCF funded several projects investigating the neuronal function in autism as well as examining visual attention in infants to create novel assessments for early detection and treatment.

High impact in ASD research in Canada is also achieved through private and government support of the Canada Research Chairs program in the research areas of Treatments and Interventions, Services, Biology, and Risk Factors:

- Dr. Evdokia Anagnostou, holds a Canada Research Chair in Translational Therapeutics in ASD, focusing on translating basic scientific findings into treatments for patients;
- Dr. Christopher Brett holds a Canada Research Chair in Cellular Science & Human Health, focusing on understanding the biology of autism using mouse models;
- Dr. Daniel Goldowitz, holds a Canada Research Chair in Developmental Neurogenetics, focusing on identifying genes that are critical to healthy brain development and function.



**Figure 7.** Canada's 2016 ASD portfolio represented by the seven research priority areas.

| Canada                        |                   |
|-------------------------------|-------------------|
| ASD Research Priority Area    | Project Count (%) |
| Screening & Diagnosis         | 5 (7%)            |
| Biology                       | 31 (42%)          |
| Risk Factors                  | 10 (13%)          |
| Treatments & Interventions    | 13 (18%)          |
| Services                      | 5 (7%)            |
| Lifespan Issues               | 5 (7%)            |
| Infrastructure & Surveillance | 5 (7%)            |
| <b>Total</b>                  | <b>74</b>         |

**Table 12.** Canada's 2016 projects aligned to the research priority areas.

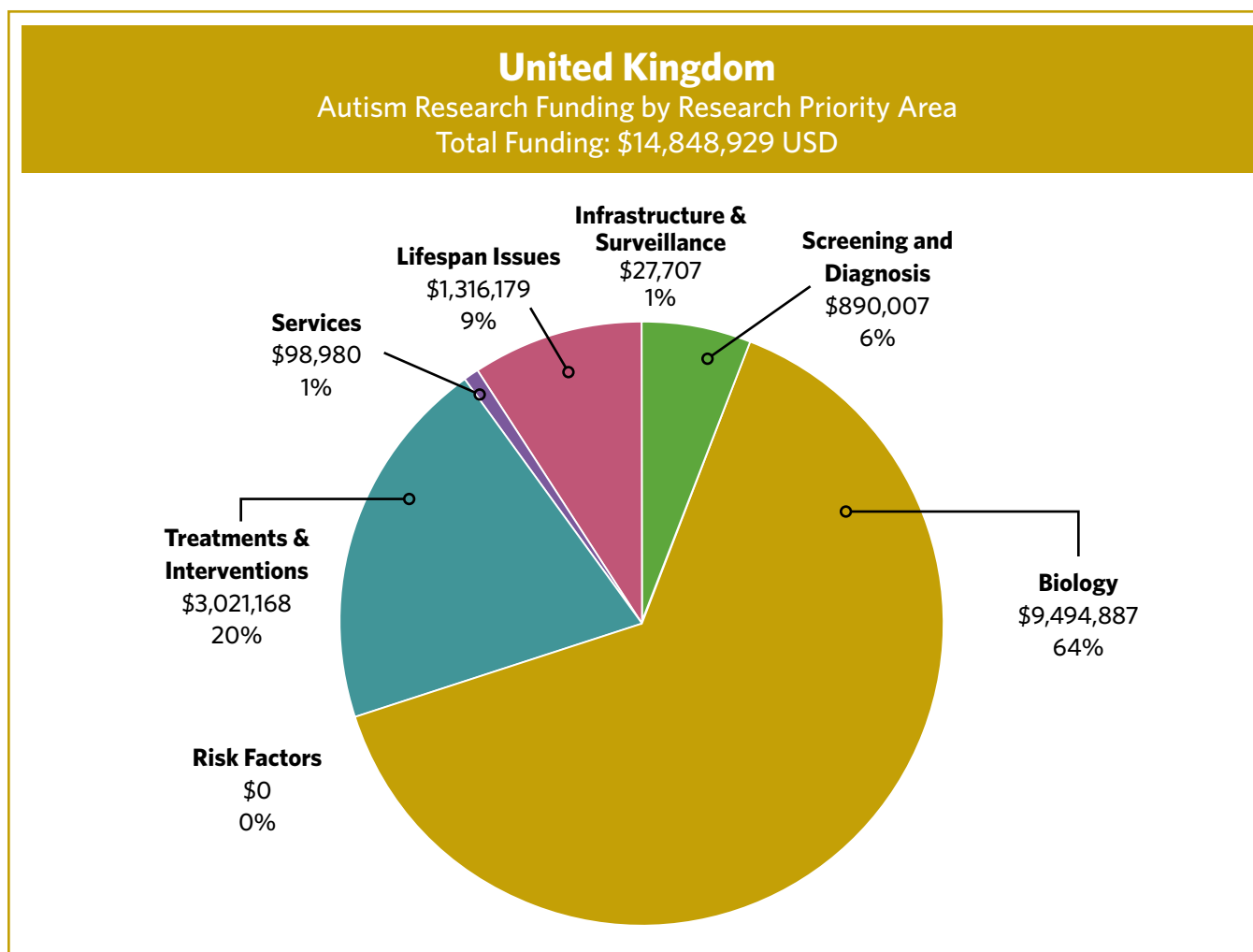
## United Kingdom's 2016 Autism Research Portfolio

The U.K. provided autism research funding for six of the seven research priority areas in 2016 (**Figure 8**). The largest portion of funding went towards **Biology** (64%). Investment in biology research in the U.K. was significant in 2016. Although investment in biology is ongoing in the U.K., the annual figure for 2016 was elevated by an uncharacteristically large grant (£2.8 million/\$4 million). The grant was awarded by the Wellcome Trust to the University of Edinburgh to improve understanding and treatment of MeCP2-related disorders. The 5-year program of work seeks to better understand MeCP2 binding in vivo; how and why gene expression is affected by varying levels of MeCP2; and will explore therapeutic options for treatment of Rett syndrome and MeCP2 Duplication Syndrome.

As with the three other countries, the U.K. supports significant investment in **Treatments and Interventions** (20%), which was the second largest funded research area among the U.K. autism research portfolio. A significantly large project included in the portfolio was the Paediatric Autism Communication Trial (PACT-G), which was funded by the National Institute for Health Research, a public body agency. The goal of this project is to bridge the gap between research and practice – the project will test a clinic-assessed treatment in home and school contexts with the hopes of demonstrating the same treatment gains in a clinical setting. In 2015, Autistica initiated a priority setting partnership to work with all those who know about and understand autism to identify the Top 10 priorities for research. The resulting priorities are largely intervention-focused. Thus, the significant investment in Treatments and Interventions represents the research appetite in the U.K. This could also go some way in explaining the lack of **Risk Factors** (0%) investment in the U.K., as this kind of research has not been a high priority within the U.K. autism community.

The U.K. has a relatively large investment in **Lifespan Issues** (9%) research. Autism and Ageing was identified as a key priority for autism research in the Autistica Research Strategy. Autistica invested in an ongoing 'Programme of Research for Autism and Ageing' at Newcastle University. Also, the U.K. funded several projects that fell into **Screening & Diagnosis** (6%), including a project supported by the Economic and Social Research Council aimed at addressing whether females with autism are being missed by current diagnostic practices. Lastly, the U.K. supported a few projects towards **Services** research (1%); and one project to support **Infrastructure and Surveillance** research efforts (1%).

Particularly for the U.K. portfolio, it is important to review the project counts for each research priority area as the U.K. funds their projects in the first year of research only. Assessing the project counts ensures evaluation of the U.K.'s autism research priorities outside of funding. For the U.K., in 2016 there were research projects in each of the seven research areas (**Table 13**). Mirroring the U.K.'s 2016 funding, **Biology** had the most projects (22 projects) followed by **Treatments and Interventions** (13 projects). The research priority areas of **Services, Lifespan Issues, and Screening and Diagnosis** each had 6 projects, while **Infrastructure and Surveillance** had 5 research projects and **Risk Factors** had one continuing project in 2016.



**Figure 8.** United Kingdom's 2016 autism portfolio represented by the seven research priority areas. Due to rounding, the percentages for each research priority area may not add to 100 and areas with less than 1% have been rounded up to 1%.

| United Kingdom                |                   |
|-------------------------------|-------------------|
| Autism Research Priority Area | Project Count (%) |
| Screening & Diagnosis         | 6 (10%)           |
| Biology                       | 22 (37%)          |
| Risk Factors                  | 1 (2%)            |
| Treatments & Interventions    | 13 (22%)          |
| Services                      | 6 (10%)           |
| Lifespan Issues               | 6 (10%)           |
| Infrastructure & Surveillance | 5 (9%)            |
| <b>Total</b>                  | <b>59</b>         |

**Table 13.** The United Kingdom's 2016 projects aligned to the research priority areas.

## United States' 2016 Autism Research Portfolio

The U.S. research funding in 2016 supported projects relevant to all seven of the research priority areas (**Figure 9**). Research towards the underlying **Biology** of ASD received the largest portion of funding (35%). NIH funds the **Autism Centers for Excellence (ACE)** program, a program that supports large research centers and multi-site networks aimed at understanding the causes and underlying biology of ASD and to find new treatments. ACE projects that emphasize uncovering biological processes include research aimed at charting the longitudinal changes in brain activity in children with ASD and relating it to observable, behavioral traits as well as research integrating genetic data with identifying biomarkers. Among U.S. funders, understanding the biological aspects of ASD are a priority of many agencies' and organizations' missions. Funding for research aimed at identifying potential causes and **Risk Factors** for ASD (24%) received the second largest investment. Investigating risk factors is heavily supported by several federal and private funders. Among federal funders, the CDC supports the **Study to Explore Early Development (SEED)**, the largest study in the U.S. identifying genetic and environmental factors that may put children at risk of ASD, conducted via six clinical sites across the U.S. and involving over 7,000 children. Also, the NIH funds the **Childhood Autism Risk for Genetics and the Environment (CHARGE)** study, which has been funded since 2003 and is a population-based epidemiological study that is examining environmental causes and risk factors for ASD. For private funders, Autism Science Foundation (ASF) funds the **Autism Sisters Project**, which supports research to understand the female protective effect and why autism is expressed differently in males than in females. Autism Speaks supports the **MSSNG initiative**, which is a collaboration between Autism Speaks, Google, and the research community to create the world's largest genomic database on autism. Simons Foundation (SF) has launched several large projects

to understand the genetic basis of ASD, including the **Simons Variation in Individuals Project (Simons VIP)** and the **Simons Foundation Powering Autism Research for Knowledge (SPARK)** project.

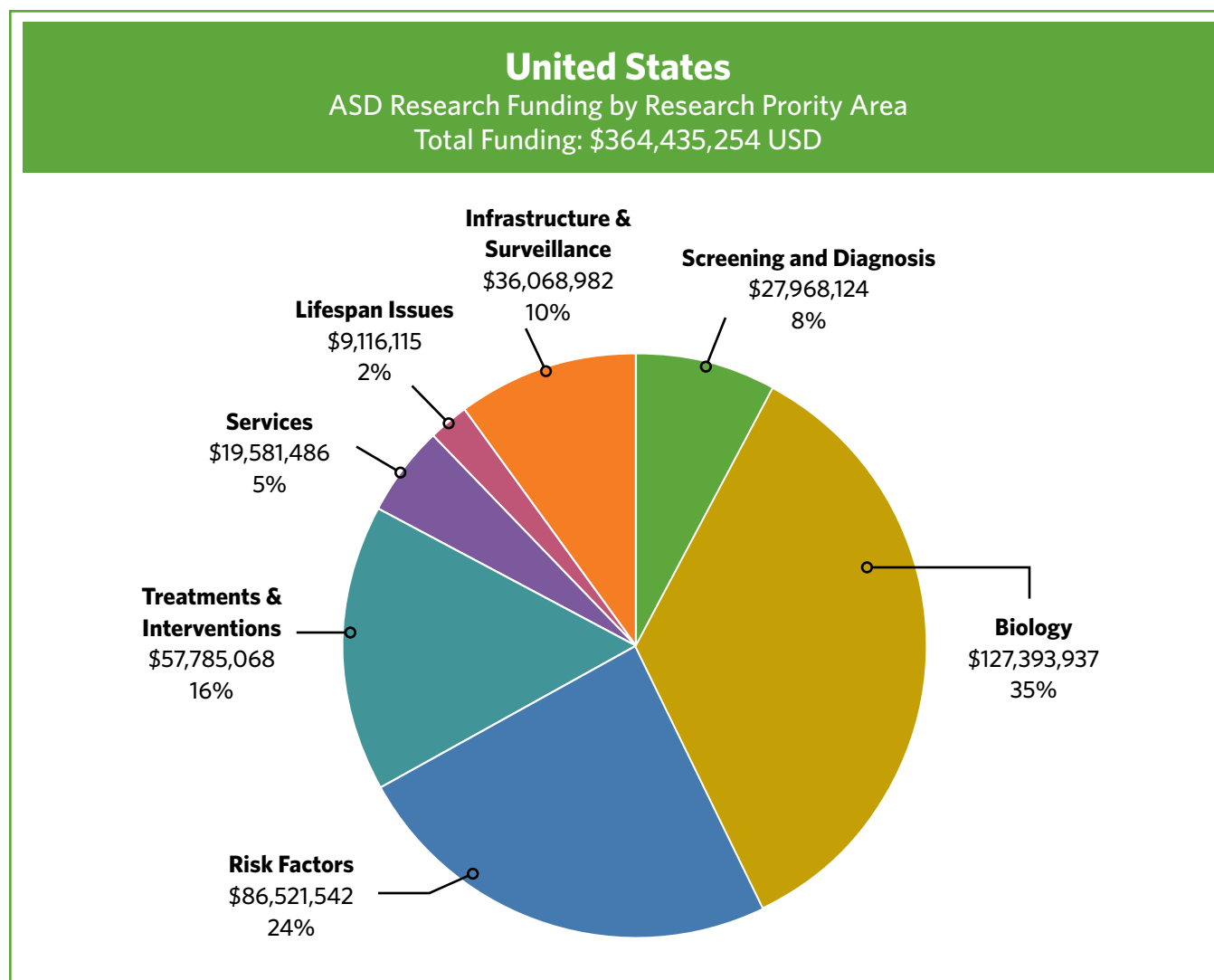
Research into **Treatments and Interventions** for ASD followed with 16% of total U.S. funding in 2016. The majority of U.S. funders contributed to projects included in the treatments and interventions research priority area. Notable initiatives are NIH's ACE program, which supports projects focused on developing early intervention programs involving joint attention and augmented language, and the **Autism Biomarkers Consortium for Clinical Trials (ABC-CT)**, a consortium developing effective treatments for social impairment in ASD using biomarkers. Also, the **Autism Intervention Research Network on Physical Health (AIR-P)** and behavioral health (**AIR-B**) are two networks of researchers seeking to advance evidence-based practices in physical health and behavioral health treatments. The AIR-P and AIR-B are collaborative research initiatives that include the federal agency, HRSA, and the private organization, Autism Speaks.

Funding towards **Infrastructure and Surveillance** was 10% of the U.S. ASD research portfolio. Projects assigned to infrastructure and surveillance included CDC's ADDM Network that provides surveillance and prevalence estimates of children with ASD, as well as projects that support major databases such as **National Database for Autism Research (NDAR)**, the **Autism Genetics Resource Exchange (AGRE)**, and **Autism Brain Net**. Research to improve **Screening and Diagnosis** of ASD was 8% of research funding in 2016. HRSA supports the **Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** initiative, which provides funding to assess screening tools for ASD, in addition to extensive services and provider training programs. NIH also funds several research projects focused on early identification

for children with ASD. Research focused on **Services** and **Lifespan Issues** were the smallest areas of funding (5% and 2% respectively). The U.S. was the largest funder of both Services (\$19.6 million, 84 projects) and Lifespan Issues (\$9.1 million, 48 projects) research, but devoted a smaller percentage of its portfolio to these issues than the other three countries. Within the Services research priority area, ED supported several projects training early intervention and early childhood special education teachers. Among the Lifespan Issues projects, the DoD-Army supported two employment-related projects for transitioning youth and adults with ASD. In part due to the prioritization of the need for more research on services and lifespan issues in the *IACC Strategic Plan*, the NIH began a new program in 2014: the 'Services Research for Autism Spectrum Disorder Across the Lifespan' (ServASD) initiative. Projects supported by this initiative focus on stimulating new research to develop and test the effectiveness of service system interventions to improve

functional and health outcomes for people with ASD at three key life stages: early childhood, transition from youth to adulthood, and adulthood. While this program has been successful, there is still a need for a greater number of researchers in this field. NIH has also launched initiatives, such as a **funding announcement**, for established investigators to redirect or expand their research programs in the area of autism services research for adults and transition- age youth with ASD.

When assessing the number of projects rather than the total funding for these projects, the portfolio is slightly different. In 2016, the number of total projects aligned with each question were as follows: **Screening and Diagnosis**, 107; **Biology**, 491; **Risk factors**, 240; **Treatments and Interventions**, 254; **Services**, 84; **Lifespan Issues**, 48; **Infrastructure and Surveillance**, 136 (Table 14).



**Figure 9.** United States' 2016 ASD portfolio represented by the seven IACC research priority areas.

| United States                 |                   |
|-------------------------------|-------------------|
| Autism Research Priority Area | Project Count (%) |
| Screening & Diagnosis         | 107 (8%)          |
| Biology                       | 491 (36%)         |
| Risk Factors                  | 240 (18%)         |
| Treatments & Interventions    | 254 (19%)         |
| Services                      | 84 (6%)           |
| Lifespan Issues               | 48 (3%)           |
| Infrastructure & Surveillance | 136 (10%)         |
| <b>Total</b>                  | <b>1360</b>       |

**Table 14.** The United States' 2016 projects aligned to the research priority areas.

# Summary and Conclusion

The *2016 International ASD Research Portfolio Analysis Report* includes Australia, Canada, the United Kingdom, and the United States and represents the first year that data on ASD research funding were collected and reported on a global scale. This report was an opportunity to assess current investments in ASD research among different countries and see areas in need of funding in the future. Data were collected from public body entities and private organizations in each country and the diverse missions of each funder are reflected within the portfolio.

In 2016, the total funding for ASD research totaled \$395.9 million and spanned 1,552 projects. The U.S. was the largest contributor with 92% of total ASD research funding. When comparing the percentage of each country's portfolio towards the seven research areas, there were similarities and differences among the four countries. All of the countries had large investments investigating the underlying biology of ASD as well as investigating and developing treatments and interventions. However, among the four countries funding varied across the other research areas.

While each country contributed funding or maintained ongoing projects in each of the seven research priority areas, research in services and lifespan issues had the least amount of combined funding and number of projects. In recent years, members of the autism community have advocated for greater funding in these areas of ASD research. The profile of funding presented in this report demonstrates that these areas are still in need of more investment. For research areas that were well-funded, the comparison of each country's portfolio provides opportunities for further collaboration and scientific progress.

Future iterations of this report will hopefully include more countries and additional funders to more fully identify ASD research efforts around the world. As the portfolio expands and we monitor research funding over several years, there is a greater opportunity to track trends in research, detect and address knowledge gaps, recognize emerging new fields, and guide future international research partnerships and priorities. Through a global unified effort and more strategic approach, the research field can accelerate the translation of science into practice that can better serve the needs of autistic people, their families, and their communities.

# Appendices

## Appendix A: List of Acronyms

---

**ACL:** United States' Administration for Community Living

**ADDN Network:** Autism and Developmental Disabilities Monitoring Network

**ARC:** Australian Research Council

**AHRQ:** United States' Agency for Healthcare Research and Quality

**ARI:** Autism Research Institute (U.S. Funder)

**ASD:** Autism Spectrum Disorder

**AS:** Autism Speaks (U.S. Funder)

**ASF:** Autism Science Foundation (U.S. Funder)

**AUD:** Australian Dollar

**Autism CARES Act:** Autism Collaboration, Accountability, Research, Education and Support Act of 2014

**Autism CRC:** Cooperative Research Centre for Living with Autism

**BBRF:** Brain and Behavior Research Foundation (U.S. Funder)

**BCF:** Brain Canada Foundation (Canadian Funder)

**CAD:** Canadian Dollar

**CARD:** Center for Autism and Related Disorders (U.S. Funder)

**CDC:** United States' Centers for Disease Control & Prevention

**CIHR:** Canadian Institutes of Health Research

**DoD – Army:** United States' Department of Defense – Army

**ED:** United States' Department of Education

**EPA:** United States' Environmental Protection Agency

**EPSRC:** United Kingdom's Engineering and Physical Sciences Research Council

**HHS:** United States' Department of Health and Human Services

**HRSA:** United States' Health Resources and Services Administration

**IACC:** Interagency Autism Coordinating Committee

**KBHN:** Canada's Kids Brain Health Network

**MRC:** United Kingdom's Medical Research Council

**NASS:** Canadian National Autism Spectrum Disorder Surveillance System

**NECC:** New England Center for Children (U.S. Funder)

**NHMRC:** Australia's National Health and Medical Research Council

**NHS:** United Kingdom's National Health Service

**NICE:** United Kingdom National Institute for Health and Care

**NIH:** United States' National Institutes of Health

**NIHR:** United Kingdom's National Institute for Health Research

**NSF:** United States' National Science Foundation

**OAR:** Organization for Autism Research (U.S. Funder)

**OARC:** Office of Autism Research Coordination

**OBi:** Ontario Brain Institute (Canadian Funder)

**PCORI:** Patient-Centered Outcomes Research Institute

**POND:** Canada's Province of Ontario Neurodevelopmental Disorders Research Network

**SF:** Simons Foundation

**SPARK:** Simons Foundation Powering Autism Research for Knowledge

**U.K.:** United Kingdom

**U.S.:** United States

## Appendix B: Methods

### Data Collection Methods

#### **Canada and United States**

The U.S. and Canada collected ASD project information through data calls to each government agency and private organization. Projects were reviewed and coded to the seven research areas by two members of the OARC team.

The funding mechanisms among funders vary, some funders provide an entire project's funding in the first year of an award while other projects receive funding annually during an award period. To maintain consistency in our reporting, funders use the same funding mechanism from year to year.

#### **United Kingdom**

U.K. data was sourced from the Dimensions database - a research grant database developed by ÜberResearch ([www.uberresearch.com](http://www.uberresearch.com)) that covers around 200 funders worldwide. All major U.K. funding organizations are included in the database, as well as many smaller organizations such as Autistica.

Search categories can be created in the Dimensions database using key words, boost terms, exclusion terms and by applying a threshold to remove the long tail of grants that mention the area of interest but are not deemed of a sufficient degree to make it into the final set of grants.

Autistica developed a search category to reasonably represent 'autism research'. The search expression was derived from the description of autism in the Research, Condition, and Disease Categorization (RCDC) thesaurus. Standard Dimensions filters for country of funder (U.K.) and start year were applied. Boost terms were selected based on descriptions of grants returned in the searches and a threshold score was applied. The search results were then manually scanned for false positives by two members of the Autistica team. Projects were reviewed and coded to the seven research areas by members of the OARC and

Autistica team.

In the U.K., all funding organizations follow the same funding mechanism. Each funder provides a project's entire funding in the first year of a project's award period. The subsequent years of a project do not receive any funding.

#### **Australia**

Australian data were initially sourced from the Dimensions database<sup>12</sup>, in a manner similar to the U.K. data, except that the country of funder specified Australia. Manual searches of publicly-available databases listing research grants awarded by government agencies (ARC and NHMRC) identified a small number of additional grants not listed in the Dimensions database. As data regarding Autism CRC investment in autism research were not available in the Dimensions database, this information was gained from publicly available annual reports published on the [Autism CRC website](#) and a direct request to the organisation for further details of their investment portfolio. Finally, the websites of other relevant Australian government entities and major Australian philanthropic organisations were also reviewed.

In Australia, the funding mechanisms mirror those in the UK, with funding recorded as a total amount provided in the first year of a project's award period, and no funding recorded in subsequent years of a project.

**Inclusion/exclusion of grants** Grants were excluded from analyses if (1) funding was awarded by a source external to Australia (n = 22), or (2) insufficient information was available regarding the grant or associated research project to determine eligibility for inclusion (n = 9).

#### **Funding Conversion**

To compare funding amounts among the countries, the Purchasing Power Parity (PPP) rate for 2016 was used to convert United Kingdom's pound sterling, the Canadian dollar, and the Australian dollar to U.S. dollars.<sup>13</sup>

<sup>12</sup> Data were sourced from Dimensions, an inter-linked research information system provided by Digital Science (<https://www.dimensions.ai>).

<sup>13</sup> 2016 Purchasing Power Parity (2016): <https://data.oecd.org/conversion/purchasing-power-parities-ppp.htm>

## Appendix C: Funder Mission Statements

---

### Australia

#### Government Agencies

##### Australian Research Council (ARC)

The [Australian Research Council \(ARC\)](#) is Australia's federal funding agency supporting fundamental and applied research and research training across all disciplines. Its purpose is "to grow knowledge and innovation for the benefit of the Australian community through funding the highest quality research, assessing the quality, engagement and impact of research and providing advice on research matters" to the Australian Government. It also brokers partnerships between researchers and industry, government, community organizations and the international community.

##### National Health and Medical Research Council (NHMRC)

The [National Health and Medical Research Council](#) is Australia's leading expert body in health and medical research. They seek to create knowledge and build research capability through investment in the highest quality health and medical research and the best researchers; drive the translation of health and medical research into clinical practice, policy and health systems and the effective commercialization of research discoveries, supporting the pursuit of an Australian health system that is research-led, evidence-based, efficient and sustainable; and maintain a strong integrity framework for research and guideline development, underpinning rigorous and ethical research and relevant and accurate guidelines, and promoting community trust.

#### Private Organizations

##### Cooperative Research Centre for Living with Autism (Autism CRC)

[Autism CRC](#) was established in 2013 and is the world's first national, cooperative research effort focused on autism, taking a whole-of-life view from diagnosis and the

early years, through the school years and into adult life. It includes 56 participant organizations and other partners based around Australia and internationally, and develops unique collaborations with the autism community, research organizations, industry and government. Their mission is to motivate, facilitate and translate collaborative autism research across the lifespan, underpinned by inclusive practices. They are committed to inclusive research practices and coproduction of outcomes with those on the spectrum and their families to ensure their research provides practical and tangible outputs that benefit the community.

##### Financial Markets Foundation for Children

The [Financial Markets Foundation for Children](#) is a charitable organization, whose purpose is the promotion of the health and welfare of children of Australia. The Foundation receives both corporate and individual donations by participants of Australia's financial community to fund research programs and a wide range of other projects designed specifically to improve the health, welfare and well-being of the future of Australia.

##### Ian Potter Foundation

The [Ian Potter Foundation](#) is a major Australian philanthropic foundation that supports and promotes excellence and innovation. Established in 1964, The Foundation has contributed over \$200 million to thousands of projects, both large and small, including on autism, with a strong track record of funding projects that respond decisively to key issues and develop our creativity and capacity as a nation. As such, The Foundation maintains a tradition of encouraging excellence and enabling innovation to facilitate positive social change.

## Canada

### Government Agencies

#### Canadian Institutes of Health Research (CIHR)

The [Canadian Institutes of Health Research](#) (CIHR) is Canada's federal funding agency for health research. CIHR's mandate is "To excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system".

### Private Organizations

#### Ontario Brain Institute

The [Ontario Brain Institute](#) (OBI) is a provincially-funded, not-for-profit research centre focusing

on maximizing the impact of neuroscience and establishing Ontario as a world leader in brain research, commercialization and care. OBI funds and manages five Integrated Discovery Programs. OBI supports ASD research through Neurodevelopmental Disorders, one of its five Integrated Discovery Programs. These pan-Ontario programs take a multi-discipline, multi-stakeholder approach to supporting research.

#### Brain Canada

[Brain Canada](#) is a charitable organization that funds innovative, paradigm-changing brain research across Canada. Brain Canada has supported Autism Research through partnerships with the Kids Brain Health Network, the Azrieli Foundation, and others.

## United Kingdom

### U.K. Research Councils

#### Economic and Social Research Council (ESRC)

The [Economic and Social Research Council](#) (ESRC) is a non-departmental public body funded by a grant-in-aid from the U.K. government. The ESRC are the U.K.'s largest organization for funding research on economic and social issues. The ESRC support independent, high quality research which has an impact on business, the public sector and civil society. At any one time ESRC supports over 4,000 researchers and postgraduate students in academic institutions and independent research institutes. Current ESRC priority areas include: mental health; housing; productivity; understanding the macro economy; climate change; innovation in health and social care; trust and global governance in a turbulent age.

### Engineering and Physical Sciences

#### Research Council (EPSRC)

The [Engineering and Physical Sciences Research Council](#) (EPSRC) is a non-departmental public body funded by a grant-in-aid from the U.K. government. The EPSRC is the main funding body for engineering and physical sciences research in the U.K. The EPSRC portfolio covers a vast range of fields from healthcare technologies to structural engineering, manufacturing to mathematics, advanced materials to chemistry. EPSRC's mission is to contribute to a healthy, connected, resilient, productive nation.

#### Innovate UK

[Innovate UK](#) is the operating name of the Technology Strategy Board, the U.K.'s innovation agency. It is a U.K. non-departmental public body reporting to the Department for Business, Energy and Industrial Strategy (BEIS). Innovate UK's mission is to accelerate U.K. economic growth by stimulating and supporting business-led innovation.

### **Medical Research Council (MRC)**

The **Medical Research Council** (MRC) is a non-departmental public body funded by a grant-in-aid from the U.K. government. The MRC's mission is to: encourage and support research to improve human health; produce skilled researchers; advance and disseminate knowledge and technology to improve the quality of life and economic competitiveness of the U.K.; and promote dialogue with the public about medical research. The MRC portfolio covers six broad areas of research: infections and immunity; molecular and cellular medicine; neurosciences and mental health; population and systems medicine; global health; and translational research.

### **National Institute for Health Research (NIHR)**

The **National Institute for Health Research** (NIHR) was established as part of the U.K. government's health research strategy 'Best Research for Best Health' (2006) and is funded by the Department of Health and Social Care. It has five objectives: to fund high quality research to improve health; to train and support health researchers; to provide world-class research facilities; to work with the life sciences industry and charities to benefit all; to involve patients and the public at every step. NIHR fund health and care research and translate discoveries into practical products, treatments, devices and procedures. They ensure the NHS is able to support the research of other funders to encourage broader investment in, and economic growth from, health research. NIHR work with charities and the life sciences industry to help patients gain earlier access to breakthrough treatments and. They train and develop researchers to keep the nation at the forefront of international research.

### **U.K. Charitable Organizations**

#### **Autistica**

As the U.K.'s leading autism research charity, **Autistica** exist to harness the potential of cutting-edge science to improve the lives of autistic people and their families. The charity's vision is a long, healthy, happy life for autistic people and their families. They fund and promote ground-breaking research, improve understanding of autism and advance new therapies and interventions. The charity has funded the set up and development of some of the most important U.K. studies and scientific assets in autism, including the BASIS and iBASIS trials, the ASD-UK family database and the Autism Brain Bank. Current Autistica priority areas include: addressing mental health and suicide; physical health; language and communication; epilepsy and autism. Autistica aim to give the autism community a voice in everything they do.

#### **British Academy**

The **British Academy** is the U.K.'s national body for the humanities and social sciences – the study of peoples, cultures and societies, past, present and future. The academy has three principal roles: as an independent fellowship of world-leading scholars and researchers; a funding body that supports new research, nationally and internationally; and a forum for debate and engagement – a voice that champions the humanities and social sciences.

#### **Wellcome Trust**

The mission of the **Wellcome Trust** is to improve health for everyone by helping great ideas to thrive. It is a global charitable foundation, both politically and financially independent. It has a £23.2bn investment portfolio and works with academia, philanthropy, business, governments and civil society around the world. Current Wellcome Trust priority areas include: maximizing the health benefits of genetics and genomics; understanding the brain; combating infectious disease; investigating development, ageing and chronic disease; connecting environment, nutrition and health.

## United States

### **Federal Agencies - Department of Health and Human Services (HHS)**

The mission of HHS is to enhance and protect the health and well-being of all Americans by providing for effective health and human services and fostering advances in medicine, public health, and social services. HHS includes more than 300 programs and 11 operating divisions covering a wide spectrum of activities.

#### **Administration for Community Living (ACL)**

Formed in 2012, ACL serves as the federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan. ACL funds the AutismNOW web resource, which provides information for the ASD community on topics including detection, intervention, education, transition from high school into early adulthood, employment, advocacy, community inclusion, aging issues, and public policy.

#### **Agency for Healthcare Research and Quality (AHRQ)**

The mission of AHRQ is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. Their portfolio includes projects to evaluate the comparative effectiveness of autism interventions and to conduct systematic reviews of the literature on topics such as autism screening and autism interventions, with the goal of evaluating the strength of the evidence supporting practices and identifying gaps in research. AHRQ also funds projects aimed at disseminating information about best practices and other findings from their reviews to researchers, practitioners, the patient community, and other stakeholders.

#### **Centers for Disease Control and Prevention (CDC)**

The mission of CDC is to create the expertise, information, and tools that people and communities need to protect their health. This is achieved through health

promotion, prevention of disease, injury and disability, and preparedness for new health threats. CDC's autism research portfolio includes projects to collect data on ASD prevalence and risk factors, and projects to improve awareness, early detection, and intervention.

#### **Health Resources and Services Administration (HRSA)**

HRSA is the primary federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable. The Maternal and Child Health Bureau (MCHB) supports autism-related programs through its Combating Autism Act Initiative (CAAI), including projects to increase awareness, reduce barriers to screening and diagnosis, promote the development of guidelines for evidence-based practices, and train health care professionals to provide screening as well as diagnostic and early, evidence-based intervention. Flagship programs include the Autism Intervention Research Networks ([AIR-B](#) and [AIR-P](#)), the Developmental Behavioral Pediatrics Research Network ([DBPNet](#)), and the Leadership Education in Neurodevelopmental and Related Disabilities ([LEND](#)) program.

#### **National Institutes of Health (NIH)**

The mission of NIH is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. The NIH supports a broad range of research on ASD, including projects on the basic neuroscience of ASD, risk factors, diagnosis, intervention, and services research. One of the flagship autism programs funded by NIH, the Autism Centers of Excellence ([ACE](#)), is a collection of research centers and networks across the country that conduct research on ASD. Since 2014, NIH has funded the [ServASD](#) initiative, which supports research to develop and test the effectiveness of service strategies to improve functional outcomes in early childhood, transition from youth to

adulthood, and adulthood. NIH also funds interdisciplinary data repositories such as the National Database for Autism Research (**NDAR**) to facilitate the sharing of autism research data among scientists worldwide.

### **Federal Agencies – Other**

#### **Department of Defense (**DoD**)**

The Department of Defense (**DoD**) is charged with coordinating and supervising all agencies and functions of the government concerned directly with national security and the U.S. Armed Forces. Within the DoD's Defense Health Research Program, the Congressionally Directed Medical Research Program's Autism Research Program (**ARP**) was established in 2007, with the mission to improve the lives of individuals with ASD by promoting innovative research that advances the understanding of ASD and leads to improved outcomes for those with ASD. The projects that the ARP funds span the scope of the IACC.

The U.S. Air Force (DOD-AF) also funds research on ASD, and is developing a multidisciplinary autism research and services program for military families, part of which involves the creation of a comprehensive registry to provide higher quality data for autism clinical and genetics research.

#### **Department of Education (**ED**)**

The mission of the U.S. Department of Education is to promote student achievement by fostering educational excellence and ensuring equal access. The department funds a portfolio of ASD-related projects relating to development and delivery of educational interventions and services, particularly for children and transition-aged youth. A large portion of ED's funding goes towards developing practitioner training as well as investment in training researchers. ED also supports funding towards a joint initiative between ED, HHS, Department of Labor, and the Social Security Administration called Promoting Readiness of Minors in Supplemental Security Income (PROMISE), which was created to foster improved health, education, and post-secondary outcomes for children ages 14-16 who receive Supplemental Security Income (SSI), as well as their families.

#### **Environmental Protection Agency (**EPA**)**

The mission of the U.S. EPA is to protect human health and the environment. EPA co-funds the Center for Children's Environmental Health (CCEH) at the University of California at Davis with the National Institute of Environmental Health Sciences (NIEHS)/ NIH, which conducts research into how environmental exposure to toxins might interact with a person's genes and immune system to influence the risk and severity of ASD.

#### **National Science Foundation (**NSF**)**

NSF is an independent federal agency, formed by Congress to promote the progress of science and to advance the national health, prosperity, and welfare. NSF funds basic research in biology, mathematics, computer science, and the social sciences as well as technology development, but it does not focus on health or disease-related research. Although NSF does not have a program focused on ASD, it funds several projects that involve basic science or technologies with the potential to be applied to ASD in the future. NSF is a leading funder of projects involving technological interventions and supports, including robotics and virtual reality technologies that could be used to enhance daily living skills and activities of individuals with disabilities.

### **Private Organizations**

#### **Autism Research Institute (**ARI**)**

ARI's mission is to meet the needs of the global autism community through research, networking, education, and support for families and people of all ages on the autism spectrum. ARI is dedicated to developing a standard of care for individuals with autism spectrum disorders and their families, and funds a range of work with a particular emphasis on investigation of the biological underpinnings of autism, including immune and metabolic pathways.

#### **Autism Science Foundation (**ASF**)**

ASF's mission is to support autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing, and

disseminating autism research. The organization also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. ASF funds the Autism Sisters Project, which recruits unaffected sisters of individuals with autism to help researchers understand the female protective effect. ASF also supports the Baby Siblings Research Consortium, a network of researchers studying the earliest behavioral and biological features of ASD. In addition, ASF funds pre- and postdoctoral trainees to conduct basic and clinical research relevant to ASD, including studies focused on a wide range of topics such as identification of biomarkers, molecular and cellular mechanisms, genetic and environmental risk factors, treatments, and service delivery.

#### **Autism Speaks (AS)**

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. AS funds a broad profile of ASD research ranging from basic neuroscience and the molecular causes of autism to implementation and testing of interventions for those diagnosed with autism. Autism Speaks supports the Autism Treatment Network (ATN), a collaboration of 14 specialty centers dedicated to providing families with state-of-the-art, multidisciplinary healthcare for children and teens affected by autism.

#### **Brain and Behavior Research Foundation (BBRF)**

BBRF funds basic neuroscience research to elucidate the molecular mechanisms underlying brain disorders and conditions. BBRF's autism research portfolio primarily includes studies on the genetics and molecular mechanisms underlying autism.

#### **Center for Autism and Related Disorders (CARD)**

CARD is one of the world's largest organizations using applied behavior analysis (ABA) in the treatment of ASD, and other related disorders. CARD's research portfolio is centered around developing new behavioral interventions, assessing existing behavioral interventions, and developing and implementing training/intervention programs for individuals on the autism spectrum from birth to age 21.

#### **Organization for Autism Research (OAR)**

The mission of OAR is to support research that directly impacts the day-to-day quality of life of those with ASD. This includes research to inform and improve education, communication, self-care, social skills, employment, behavior, and adult and community living. In this context, it extends to issues related to family support, the efficacy of service delivery systems, and demographic analyses of the autism community.

#### **New England Center for Children (NECC)**

The New England Center for Children is a private, nonprofit autism research and education center dedicated to transforming the lives of children with autism worldwide through education, research, and technology. NECC strives to be a global leader in the provision of effective, evidence-based educational services for the millions of under-served children with autism and their families.

#### **Patient-Centered Outcomes Research Institute (PCORI)**

PCORI helps people make informed healthcare decisions and improves healthcare delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

#### **Simons Foundation (SF)/**

#### **Simons Foundation Autism Research Initiative (SFARI)**

The mission of SF is to advance the frontiers of research in mathematics and the basic sciences. SF's single largest initiative is the Simons Foundation Autism Research Initiative (SFARI), which seeks to improve the diagnosis

and treatment of ASD by funding, catalyzing, and driving innovative research of the greatest quality and relevance. The SF ASD portfolio includes research on genetic and cellular factors underlying autism, identification of genetic and environmental risk factors, and development of potential treatments. SFARI supports **SPARK**, a large autism research project aimed at collecting medical and genetic information from individuals with autism and their family in an effort to increase the power of autism research for knowledge.

## Contributors

---

### United States

#### OARC

National Institute of Mental Health  
National Institutes of Health  
6001 Executive Boulevard, Room 7215,  
Rockville, MD 20892  
USA

Email: [IACCPublicInquiries@mail.nih.gov](mailto:IACCPublicInquiries@mail.nih.gov)

Website: <http://www.iacc.hhs.gov>

#### Susan A. Daniels, Ph.D.

Director

#### Oni Celestin, Ph.D.

Science Policy Analyst

#### Julianna Rava, M.P.H.

Science Policy Health Analyst

### United Kingdom

#### Autistica

St Saviour's House  
39-41 Union Street  
London SE1 1SD  
United Kingdom

Email: [friends@autistica.org.uk](mailto:friends@autistica.org.uk)

Website: <https://www.autistica.org.uk>

#### James Cusack, Ph.D.

Director of Science

#### Cat Hughes, Ph.D.

Research and Grants Officer

#### Georgina Warner, Ph.D.\*

Research Manager

### Canada

#### CIHR

Website: <http://www.cihr-irsc.gc.ca/e/8602.html>

#### Elizabeth Theriault, PhD

Senior Consultant, Strategic Initiatives  
Institute of Neurosciences,  
Mental Health and Addiction

#### Carolina Koutras, PhD\*

Team Lead, Projects and Initiatives  
Institute of Neurosciences,  
Mental Health and Addiction

### Australia

#### Macquarie University

Balaclava Rd, Macquarie Park  
New South Wales 2109  
Australia

Website: <http://www.mq.edu.au>

#### Liz Pellicano, PhD

Professor of Educational Studies  
Faculty of Human Sciences

Email: [liz.pellicano@mq.edu.au](mailto:liz.pellicano@mq.edu.au)

#### Jacquiline den Houting, PhD

Postdoctoral Research Fellow  
Department of Educational Studies  
Faculty of Human Sciences

Email: [jac.denhouting@mq.edu.au](mailto:jac.denhouting@mq.edu.au)

\*Individual contributed to the report but is no longer affiliated with the listed organization or agency.





