



# 2020 Annual Progress Report

## Understanding and Preventing Suicidal Behaviour in Autistic People

Darren Hedley, PhD  
SPA Research Fellow/Project CI

**December, 2020**

This report was prepared by Darren Hedley, PhD and Kat Denney for Suicide Prevention Australia

## Contact

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## Suggested reference

Hedley, D. & Denney, K. (2020). *2020 Annual Progress Report: Understanding and Preventing Suicidal Behaviour in Autistic People*. Melbourne, Victoria: La Trobe University.

# Executive summary

- Advisory/lived experience & stakeholder groups established
- Ethics was submitted and approved, including approval to link to Autism CRC longitudinal data
- Request to link data from Autism CRC SASLA/ALSAA studies approved by respective Autism CRC project leaders
- Data collection for **Study 2** started **October, 2020**
- Request to access existing Autism CRC SASLA/ALSAA longitudinal data for **Study 1** was approved and data were received from both studies **November, 2020**
- 1 x in press book chapter, 1 x publications submitted (under review), 1 x study pre-registration complete; 2 x conference presentations accepted (ASfAR, 2020), 2 x submitted (INSAR, 2021); 2 x invited presentations (Nationwide Children's Hospital, OH, USA; Duke University, NC, USA)

# Project Team

- **SPA Research Fellow/Project CI**
  - Darren Hedley, PhD; OTARC/School of Psychology & Public Health/La Trobe University
- **Research team**
  - Kat Denney (RA); Perrin Date (lab manager); Dr Simon Bury (Psychologist)
- **Co-investigators**
  - Angela Clapperton, PhD; University of Melbourne/Melbourne School of Population and Global Health
  - Mirko Uljarević, MD, PhD; University of Melbourne/School of Psychological Sciences
  - A/Prof. Jo Robinson, PhD; University of Melbourne/Centre for Youth Mental Health/Orygen
  - Prof. Cheryl Dissanayake, PhD; OTARC/School of Psychology & Public Health/La Trobe University
  - Prof. Julian Trollor, MD; University of New South Wales, Department of Developmental Disability Neuropsychiatry
  - A/Prof. Mark Stokes, PhD; Deakin University/Faculty of Health, School of Psychology

# Research Activity Milestones

- The primary research activity target milestone for the project was to have the first manuscript submitted by Dec 31, 2021. Currently the project has produced one book chapter (in press) and one academic manuscript (revisions, under review, PLoS One). The project has also been successful in securing longitudinal data for the third manuscript which will be developed in early 2021.

| 1.5 | Research Activity Target Dates and Milestones: | Number | Milestone              | Due Date     |
|-----|--|--------|------------------------|--------------|
|     |  | 1      | Manuscript 1 submitted | Dec 31, 2020 |
|     |  | 2      | Manuscript 2 submitted | Jan 31, 2022 |
|     |  | 3      | Manuscript 3 submitted | May 31, 2022 |

# Research Activities Performance Metrics

|            |  |   |
|------------|--|---|
| <b>1.6</b> | Research Activities Performance Metrics: | <ol style="list-style-type: none"><li>1. Contribute to and facilitate the development of guidelines and recommendations for government/policy makers for preventing suicide in autistic people in conjunction with stakeholders and partner organisations (ASPECT, AMAZE, UNTAPPED, ORYGEN);</li><li>2. Minimum of 3 open sourced academic manuscripts in leading peer reviewed journals;</li><li>3. Distribution of research findings at international/national conferences, media releases in partnership with Untapped (PO), autism peak bodies (ASPECT, AMAZE), OTARC;</li><li>4. Develop and distribute web resource for stakeholders (autistic individuals, mental health clinicians) through established partnerships (ASPECT, AMAZE, UNTAPPED, ORYGEN).</li></ol> |
|------------|--|---|

# Research Activities Performance Metrics cont'd

- Engaged with individuals from AMAZE (Victoria peak autism body), ASPECT (NSW peak autism body), Orygen, Untapped, researchers from UNSW/Black Dog, with regards to improving mental health and suicide prevention services for autistic people (1)
- Contribution to discussions with AMAZE and Victorian Government DHHS and HOPE project to improve mental health and suicide prevention services for autistic people (1)
- Production of 1 x book chapter and 1 x manuscript. Data for 1 x manuscript has been secured and will be completed in the first half of 2021 (2)
- Presented research findings at 1 x national conference and was an invited speaker at 2 x international talks (3)
- In conjunction with LTU academics Dr Carina Chan and Dr Karien Hill, and UNSW/Black Dog researcher Dr Mark Deady, we are incorporating autism specific information into an online suicide prevention resource developed by Dr Hill (4)
- In conjunction with research team members, autistic people, and original authors, we have modified a suicide ideation screening instrument (SIDAS) and clinical assessment tool (SAK) for use by autistic people. It is hoped these instruments will assist mental health clinicians in identifying suicide risk in autistic people (4)

# Key Dates June-Dec 2020

- 1/6/2020 – Funding agreement LTU/SPA
- 1/6/2020 – Identification & invitations to lived experience advisory group members
- 3/6/2020 – 1st advisory group meeting with autistic members (Chair DH, members 4 x lived experience)
- 15/6/2020 – Establishment of project stakeholder group members
- 30/7/2020 – Project ethical approval from LTU Human Research Ethics Committee (HEC20235; 13/7/2020-25)
- 11/8/2020 – Attendance at Mindful Autism Assessment Capability and Capacity (MAACC) governance group meeting. MAACC project works with (DHHS), Victoria, to increase capacity within existing mental health services to better serve the needs of autistic people
- 21/8/2020 – Consult w/ AMAZE (State autism peak body) re Victoria State Government royal commission recommendations for improving access of autistic people to mental health services in Victoria



# Key Dates June-Dec 2020 cont'd

- 1/9/2020 – Addition of Dr Simon Bury (registered psychologist) to study team to assist w/ follow-up of at risk participants
- 2/9/2020 – Project website launched (<https://tinyurl.com/AutismWellbeingStudy>)
- 4/9/2020 – Meeting w/ AMAZE Victoria & Department of Health and Human Services (DHHS) to consult on Mental Health Royal Commission Post-suicidal Engagement (HOPE) program
- 4/9/2020 – Collaboration w/ Dr Carina Chan (LTU Bendigo) & Dr Karien Hill to incorporate autism information into a new online suicide prevention resource, w/ aim of making prevention information available to autistic people and the people who support them.
- 28/9/2020 – Research collaborative agreement Untapped/LTU signed
- 30/9/2020 – Research collaborative agreement Deakin University/LTU signed

# Key Dates June-Dec 2020 cont'd

- 30/9/2020 – 1st recruitment advertisement went out via Study of Australian School Leavers with Autism (SASLA) newsletter (<https://mailchi.mp/a26b8d77aae4/saslaseptembernewsletter-1575334?e=7b2182b4d7>) (**Study 2**)
- 1/10/2020 – Kat Denney commenced work as project Research Assistant (RA), p/t through June, 2021
- 14/10/2020 – Addition of NIH Coronavirus Impact Scale (CIS; Kaufman, 2020) & Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007) to study test battery to control for potential COVID-19 impacts
- 26/10/2020 – Research collaborative agreement University of Melbourne/LTU signed
- 28/10/2020 – Combined SASLA/ALSAA project request approved, releasing longitudinal data for analysis (**Study 1**)
- 12/11/2020 – Pre-registration made public for manuscript “Positive mental health as a buffer between depression and suicidal ideation in autistic adolescents and adults” in OSF <https://osf.io/dhnw8/>
- 16/11/2020 – Research collaborative agreement UNSW/LTU signed

# Key Dates June-Dec 2020 cont'd

- 20/11/2020 – 1<sup>st</sup> recruitment advertisement went out via Australian Longitudinal Study of Autism in Adulthood (ALSAA) newsletter (<https://mailchi.mp/e501a4b4c9e4/the-australian-longitudinal-study-of-autism-in-adulthood-alsaa-update-summer-4721561?e=17a29209c6>)
- 4/12/2020 – 1st full stakeholder meeting & presentation of 2020 Annual Report

# Timeline Jun-Dec 2020 Planned

| Activity                         |  | June | July | August | September | October | November | December |
|----------------------------------|--|------|------|--------|-----------|---------|----------|----------|
| Annual report                    |  |      |      |        |           |         |          |          |
| Final report                     |  |      |      |        |           |         |          |          |
| Establish advisory group         |  |      |      |        |           |         |          |          |
| Advisory group meeting           |  |      |      |        |           |         |          |          |
| Study 1 (ACRC longitudinal data) | Retrieve data from ACRC                            |      |      |        |           |         |          |          |
|                                  | Analyze data                                       |      |      |        |           |         |          |          |
|                                  | Write-up & submit                                  |      |      |        |           |         |          |          |
| Study 2 (ACRC follow-up)         | Submit ethics LTU                                  |      |      |        |           |         |          |          |
|                                  | Ethics approved                                    |      |      |        |           |         |          |          |
|                                  | Data collection (recruitment & interviews) @3 p/wk |      |      |        |           |         |          |          |
| Develop & deliver online content |  |      |      |        |           |         |          |          |
| Academic output                  | Chapter (Palgrave-Macmillan)                       |      |      |        |           |         |          |          |
|                                  | Manuscript 1                                       |      |      |        |           |         |          |          |
|                                  | Manuscript 2                                       |      |      |        |           |         |          |          |

# Timeline Jun-Dec 2020 Actual

| Activity                         |  | June              | July              | August            | September         | October           | November          | December          |
|----------------------------------|--|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| Annual report                    |  |                   |                   |                   |                   |                   |                   | Completed on time |
| Final report                     |  |                   |                   |                   |                   |                   |                   |                   |
| Establish advisory group         |  | Completed on time | Completed on time | Completed on time |                   |                   |                   |                   |
| Advisory group meeting           |  | Completed on time |                   |                   |                   |                   |                   | Completed on time |
| Study 1 (ACRC longitudinal data) | Retrieve data from ACRC                            |                   |                   |                   | Delayed           | Delayed           | Completed on time |                   |
|                                  | Analyze data                                       |                   |                   |                   |                   |                   | Delayed           | Delayed           |
|                                  | Write-up & submit                                  |                   |                   |                   |                   |                   |                   | Delayed           |
| Study 2 (ACRC follow-up)         | Submit ethics LTU                                  | Completed on time | Completed on time | Completed on time |                   |                   |                   |                   |
|                                  | Ethics approved                                    |                   | Completed on time | Completed on time |                   |                   |                   |                   |
|                                  | Data collection (recruitment & interviews) @3 p/wk |                   |                   |                   |                   | Completed on time | Completed on time | Completed on time |
| Develop & deliver online content |  |                   |                   |                   |                   |                   |                   |                   |
| Academic output                  | Chapter (Palgrave-Macmillan)                       | Completed on time | Completed on time | Completed on time | Completed on time | Completed on time |                   |                   |
|                                  | Manuscript 1                                       |                   | Completed on time | Completed on time | Completed on time | Completed on time |                   |                   |
|                                  | Manuscript 2                                       |                   |                   |                   | Delayed           | Delayed           | Delayed           | Delayed           |
| <b>Legend</b>                    |  |                   |                   |                   |                   |                   |                   |                   |
| Completed on time                |  | Completed on time |                   |                   |                   |                   |                   |                   |
| Delayed                          |  | Delayed           |                   |                   |                   |                   |                   |                   |

# Stakeholder Group

- Established in June/July 2020
- Includes a diverse range of members from 4 States (NSW, VIC, SA, QLD)\*
  - People with lived experience ( $n = 4$ )\*
  - Family members ( $n = 3$ )
  - Researchers ( $n = 15$ ; Macquarie University, Deakin University, UNSW, Melbourne University, Orygen, Mindful; ANU; LTU/OTARC)\*
  - Special Interest Groups ( $n = 5$ ; AMAZE, ASPECT, Untapped)\*
  - Clinicians/practitioners ( $n = 4$ )\*

\*Some individuals are represented in more than one group

# Lived Experience Advisory Group

- The project advisory group consists of 4 people with lived experience
- The group had its 1<sup>st</sup> meeting on June 3, 2020. Members were compensated financially for their time
- The primary discussion was around the role of the group within the context of the study
- It was agreed that the group would serve in an advisory capacity adopting a consultative approach, and where feasible to do so, would co-produce aspects of the project
- Co-production efforts to date include significant contribution to screening & assessment tools, conference submission, and co-authorship of manuscript #2

# Screening & Assessment Tool Development

- **WHAT WE DID:** We worked with the original authors, a panel of experts including academic and clinical psychologists, psychiatrist, suicide prevention experts, autistic academic, autistic consultant, and a panel of 10 autistic adults (representing gender, cultural, mental health, suicide behaviours, and ability diverse populations) to modify and co-produce a suicide ideation screening instrument (SIDAS-M) and a risk screener (SAK-M) for use in the autistic population. Modifications included improved clarity of language and incorporation of “Easy English”, visual analogue scales, and provision of response exemplars.
  - A) Suicidal ideation Attributes Scales (SIDAS; van Spijker et al., 2014; thanks to Professor Philip Batterham, Australian National University)
  - B) Suicide Assessment Kit Suicide Risk Screener (SAK; Deady et al., 2015; thanks to Dr Mark Deady, UNSW)
- **WHY WE DID IT:** There are currently no available suicide risk assessment instruments developed for use by autistic people. Research has shown that existing instruments can be difficult and confusing for autistic people to complete.
- **WHAT WE HOPE TO FIND:** If SIDAS-M and SAKS-M are found to perform well compared to the non-modified instruments we are including in our study, we hope that they will be useful for clinicians to identify suicide risk in autistic people.



# Study 2 Recruitment

- Despite COVID-19 impacts on research generally, we estimate that we are on track to recruit a sufficiently sized sample for the study to be feasible (i.e., sufficient data for publication)
- We have had assistance from Autism CRC, SASLA and ALSAA studies
  - General advertising via quarterly newsletters and Autism CRC main website
  - Repeated direct emails via participant databases
- Potential pool
  - combined SASLA/ALSAA baseline sample  $N = 254$
- Study target
  - Quantitative analysis:  $n = 156$  (feasible,  $n = 60$ )
  - Qualitative analysis:  $n = 50$  (feasible,  $n = 30$ )
- Recruitment to date
  - $n = 71$  completed an expression of interest (EOI) and are proceeding through the study;  $n = 6$  did not consent or not eligible (2 x no diagnosis of autism; 2 x not in Autism CRC studies; 2 x dropout following EOI)

# Risk management

- 92% of participants completing the 1<sup>st</sup> data collection point are triggering a risk response
- 53% of participants are being followed up with a check-in by the CI (DH)
- 38% of participants (Mod/High risk) are being followed up with a risk assessment by registered psychologist (SB/MS)
- Presentations include low level current or past suicide ideation to disclosure that it is “likely” they will attempt suicide in the future
- All triggered responses are reviewed and assessed for risk level (LOW/MOD/HIGH) by CI (DH) and senior researcher/registered psychologist (MS) per study protocol
- All triggered responses are followed with contact from the research team, which in MOD/HIGH risk cases includes a risk assessment by a registered psychologist from the team (MS/SB)
- All triggered responses are sent a resource letter with contact information (e.g., Lifeline, Beyond Blue)
- In one case phone was cut-off during risk assessment. Follow-up was made by email after several attempts to reconnect with phone, and participant confirmed they were safe. Participant subsequently completed an interview (STRAIN) with the CI (DH), who confirmed participant was not at immediate risk.

# Participant feedback

- In general participants have felt the topic is important, and have been happy to receive information about the study via telephone call with the project CI (DH) prior to commencing the study
- Participants have generally viewed follow-up phone calls positively, and have thanked us for showing concern for their wellbeing
- We have received feedback from one participant who found the STRAIN (lifetime stress) assessment (administered as a telephone interview) was not what they expected and they expressed they were dissatisfied and frustrated with the instrument due to:
  - “closed question format is inadequate for autistic people”
  - questionnaire was not about “autistic suicide”
  - did not provide participant an opportunity to discuss their experience with suicidal thinking
- Project CI (DH) responded to participant, explained context/reason for administering STRAIN, and assured participant that the project includes a qualitative study that will be commenced in 2021 following quantitative data collection

# Incidents reported to ethics

- None (4/12/2020)

# Upcoming

- Study newsletter to be sent January 2021, including tips for developing a safety plan
- 3-month interviews will commence February 2021 and continue through March/April 2021
- Second recruitment push planned for February-March 2021
- Qualitative interviews planned to commence mid-2021, Q's to be developed w/ lived experience advisory group as well as seeking input from participants (via newsletter)

# Academic output

- **Pre-registration**

- Hedley, D., den Houting, J., Uljarević, M., Clapperton, A., Hayward, S. M., Dissanayake, C., Robinson, J., Trollor, J., & Stokes, M. A. (2020). Pre-registration: Positive mental health as a buffer between depression and suicidal ideation in autistic adolescents and adults. *Open Science Foundation*. Doi:10.17605/OSF.IO/DHNW8

- **Accepted**

- Hedley, D., Hayward, S. M., Clarke, A., Stokes, M., & Uljarević, M. (2020, in press). *Suicide and autism: A lifespan perspective*. In Stancliffe, R., Wiese, M. Y., McCallion, P., & McCarron, M. (Eds.), *End of life and people with intellectual and developmental disability: Contemporary issues, challenges, experiences and practice*. UK: Palgrave Macmillan.

- **Submitted/under review**

- Hedley, D., Uljarević, M., Cai, R-Y., Bury, S. M., Stokes, M., & Evans, D. W. (revisions). Domains of the Autism Spectrum Disorder phenotype, cognitive control, and rumination as transdiagnostic predictors of DSM-5 suicide risk. *PLoS One*.
- Brown, C., Stokes, M., Fuller-Tyszkiewicz, M., Krug, I., & Hedley, D. (submitted). Hiding in plain sight: How mental health conditions overshadowed autism diagnosis in women.

# Conferences and Presentations

- **Complete**

- Hedley, D., Uljarević, M., Cai, R-Y., Bury, S. M., Stokes, M. A., & Evans, D. W. (2020). *Autism domains as transdiagnostic predictors of DSM-5 suicide risk*. Oral presentation (virtual) at the 5th Australasian Society for Autism Research (ASfAR) conference. New Zealand, December 10-11
- Hedley, D., Hayward, S. M., Clarke, A., Uljarević, M., & Stokes, M. A. (2020). *Suicide and autism*. Poster presented at the 5th Australasian Society for Autism Research (ASfAR) conference. New Zealand, December 10-11.
- Hedley, D. (2020). *From employment to mental health & suicide prevention*. Invited presentation at the Duke Center for Autism and Brain Development 2020-2021 Autism Speaker Series, USA, Nov 4.
- Hedley, D. (2020). *From employment to mental health & suicide prevention*. Alumni award recipient talk at the Nationwide Children's Hospital, USA, Nov 4.

- **Submitted**

- Hedley, D., Batterham, P., Gallagher, E., Denney, K., Hayward, S., Uljarević, M., Bury, S., Clapperton, A., Robinson, J., Trollor, J., & Stokes, M. A. *Development of the Suicide Ideation Attributes Scale-Modified (SIDAS-M) in autistic adults*. Submitted to the International Society for Autism Research Annual Meeting, Boston, MA, May 6-9, 2021.
- Hedley, D., den Houting, J., Hayward, S., Uljarević, M., Bury, S., Lawson, L., Clapperton, A., Haschek, A., Dissanayake, C., Robinson, J., Trollor, J., & Stokes, M. A. *An examination of the buffering hypothesis of suicide risk in young autistic adults: Does mental wellbeing buffer the effect of depression on suicidal ideation?*. Submitted to the International Society for Autism Research Annual Meeting, Boston, MA, May 6-9, 2021.

# Acknowledgements

- Dr Mark Deady (UNSW)
- Professor Phillip Batterham (ANU)
- SASLA team (Prof. Amanda Richdale, Dr Lauren Lawson, Alex Haschek)
- ALSAA team (Dr Samuel Arnold, Sara Walker)
- Autism CRC (Sally Vidler)
- The participants



# References

- Deady, M., Ross, J. & Darke, S. (2015). *Suicide Assessment Kit (SAK): A comprehensive assessment and policy development package*. Sydney: National Drug and Alcohol Research Centre.
- Van Spijker, B.A.J., Batterham, P.J., Calear, A.L., Farrer, L., Christensen, H., Reynolds, J. & Kerkhof, A.J.F.M. (2014). The Suicidal Ideation Attributes Scale (SIDAS): Community-based validation study of a new scale for the measurement of suicidal ideation. *Suicide and Life-Threatening Behavior*, 44 (4), 408-419.



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