# Supporting the decision-making of adults with intellectual disabilities in the current Irish context

## Carers' perspectives

Dr Laura Coffey and Ms Hannah Casey

Department of Psychology
Assisting Living and Learning Institute
Maynooth University

# Who we are

## Dr Laura Coffey

**Assistant Professor/Lecturer**
Member of ALL Institute

## Prof. Deirdre Desmond

**Professor**
Co-Director of ALL Institute

## Ms Hannah Casey

**PhD Student**
Member, blog editor of ALL Institute

# Workshop overview

01 Setting the scene

02 Our research findings to date

03 Where do we go from here?

04 Your views and experiences

01

# Setting the scene

02

# Research findings

# Five iterative phases of PhD

## Phase 1

**Systematic review** of the literature

## Phase 2

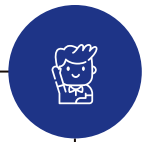
**COVID survey** of professional and family carers

## Phase 3

**Environmental scan** of available online resources

## Phase 4

**Focus groups** with adults with intellectual disabilities, professional and family carers



## Phase 5

**World Café style feedback session** with focus group participants

# Phase 1
# Systematic review

Aims:

1. How everyday decision-making is perceived and/or experienced by adults with intellectual disability, their care partners and direct care support workers
2. What techniques/approaches to decisional support are used in this context
3. Barriers/facilitators to effective decisional support encountered

# Phase 2
# COVID survey

- Online survey July – December 2021
- Aim: To explore the experiences of professional and family carers in supporting people with intellectual disabilities to make their own decisions during these restrictions
- 16 respondents (8 professional, 8 family)
- Three themes: 1) Centring the Person; 2) Adapting to COVID; 3) Restricted Lives

# Theme 1: Centring the person

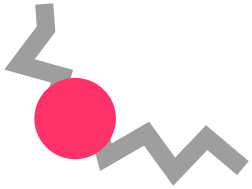
“He is always asked his views on trips, feeling comfortable in certain situations.”

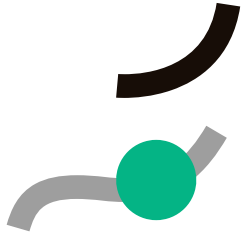
**—Family member**

# Theme 2: Adapting to COVID

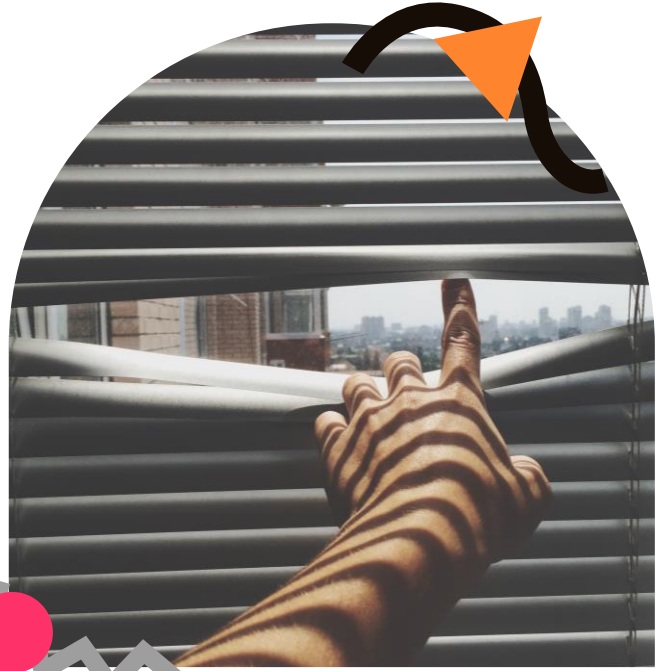
"As we were unable to meet in person due to the restrictions, we were not involved with her the way we normally would. During times when she was upset or worried, we were dealing with her over the phone."

**—Family member**





# Theme 3: Restricted lives



“My son suffered during the lockdown as everything he loved was curtailed. No sport and only telephonic support from his keyworker.”

**—Family member**

# Conclusions for family carers

01

Limited support for people with intellectual disabilities who use day or outreach services

02

Family carers often had little to no support from services during the lockdown

03

Greater emphasis on remote support access needed for families supporting someone living at home

# Phase 3
# Environmental scan

- Aim: To establish what free online resources the average professional or family carer, or person with intellectual disabilities, would find or have access to if they were to search the web
- Combination of Google search results and academic/industry expert suggestions
- First 100 search results taken
- Three phases of analysis: 1) Relevance to ADM in daily life;  2) Quality of content; 3) Accessibility of content

# Phase 3
# Environmental scan results

- Final tally of 14 online resources
- Only two were designed for people with intellectual disabilities
- Most resources found were targeted towards professional carers
- Resources for family carers often focused on the legal side of everyday application, e.g., advanced care planning
- Conducted before commencement of ADMA – Decision Support Service has since launched, with more resources available for families to access

# Phase 4
# Focus groups

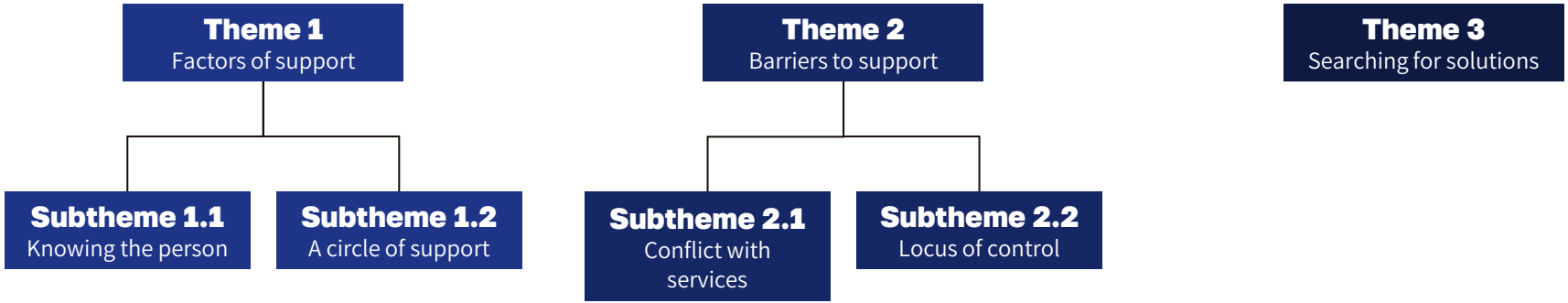
Separate focus groups for 1) supervisory staff, 2) floor staff, 3) family carers, and 4) people with intellectual disabilities

Two disability organisations as recruitment partners

Family carer focus groups:

- Ten participants across two groups
- 8 female, 2 male
- 1.5 to 2 hours

# Phase 4
# Family carer themes

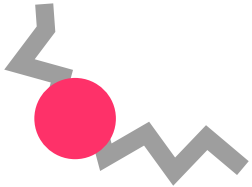


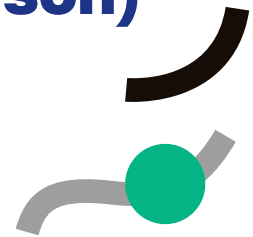
# Theme 1: Factors of support

“"So [DAUGHTER], if she doesn't want to answer a question, or you're asking her something she's not clued into you, she'll always say yeah. So I have to tell everyone. If you ask [DAUGHTER] would you like to do such thing and she says yeah, then you really have to- home in..."

**—Family member**

**(subtheme 1.1: knowing the person)**



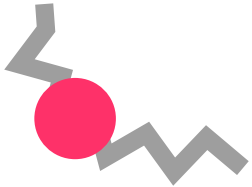


# Theme 1: Factors of support

"I'm always hoping like- my son is going to build up the road eventually. And that that she'd be able to live in the house and continue what we've set up and go in and out and he'll keep an eye on her you know, that's what you're hoping you know."

**—Family member**

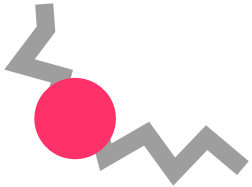
**(subtheme 1.2: a circle of support)**



# Theme 2: Barriers to support

“And there's excuses like well we can't divide the money between the house- residential home and day service since the money's all coming out of the one pot so to speak. But I don't really understand it, you know? So it's a difficult- it's a difficult.”

**—Family member**
**(subtheme 2.1: conflict with services)**



# Theme 2: Barriers to support

“I think the assisted decision-making process, and the fact they're all considered to be adults now and able to make- you have to give them- they're all to be given the opportunity to make their own decisions em, I personally don't know if [DAUGHTER] has that level of intelligence that she can take something, look at it logically and say yeah, I want to do that, or yeah that would be good for me- I'm just not convinced.”

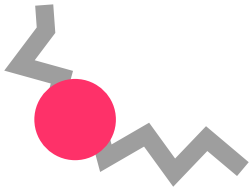
**—Family member**

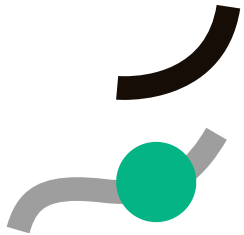
**(subtheme 2.2: locus of control)**

# Theme 3: Searching for solutions

“Well I think there should be a structure, a proper structure where you can sit down with staff, and it's one person, not ringing and talk to one person and then ring later and it's [someone else]”

**—Family member**





# Phase 5
# World Café feedback session

Two feedback sessions, one for each service – mix of professional carers, family carers and people with intellectual disabilities

Four family members participated across both groups, all female

Short presentation followed by mini group discussions of three questions:

1. How do you feel about the conclusions that were made?
2. Are there any conclusions you feel I missed?
3. Are there any points you did not get to share that you would like to share now?

After 20 minutes, participants moved groups to discuss the next question

# Family focus group conclusions

## 1.

Our **knowledge of the person** means we are a key part of the support network they need during decision-making

## 2.

We want to **work together** with staff and our loved one to get the best end result in decision making support

## 3.

We think supported decision-making sounds good in theory, but want to make sure it is done in a **flexible** way that allows for grey areas

## 4.

We worry about how often staff change within services, and getting access to more specialist help when we need it

## Saturn

Saturn is a gas giant and has several rings. It's composed of hydrogen and helium. It’s the sixth planet from the Sun

## Jupiter

Jupiter is a gas giant and the biggest planet in the Solar System. It's the fourth-brightest object in the night sky

# Family focus group conclusions

# 03

# Future directions

04

# Your views

# Two ideas

## Mercury

Mercury is the closest planet to the Sun and the smallest one in the Solar System—it's only a bit larger than the Moon. This planet's name has nothing to do with the liquid metal, since Mercury was named after the Roman messenger god

## Venus

Venus has a beautiful name and is the second planet from the Sun. It's terribly hot—even hotter than Mercury—and its atmosphere is extremely poisonous. It's the second-brightest natural object in the night sky after the Moon

# Four ideas

## Mars

Despite being red, Mars is actually a cold place. It's full of iron oxide dust, which gives the planet its reddish cast, and it’s made of basalt

## Venus

Venus has a beautiful name and is the second planet from the Sun. It’s terribly hot, even hotter than Mercury. It has a poisonous atmosphere

## Jupiter

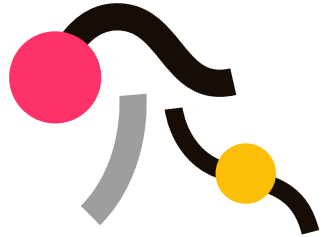
Jupiter is a gas giant and the biggest planet in the Solar System. It's the fourth-brightest object in the night sky. It was named after a Roman god

## Saturn

Saturn is a gas giant and has several rings. It's composed mostly of hydrogen and helium. It’s the sixth planet from the Sun

“This is a quote, words full of wisdom that someone important said and can make the reader get inspired.”

**—Someone Famous**



# 333,000

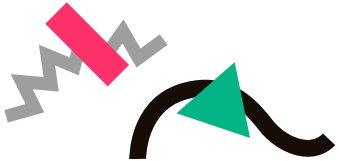
The Sun’s mass compared to Earth’s

# 9h 55m 23s

Jupiter’s rotation period

# 386,000 km

Distance between Earth and the Moon



# 4,498,300,000

Big numbers catch your audience’s attention

# Editable graph

**35%**

**Team 1**

Mars is very cold

**30%**

**Team 2**

Venus is very hot

**20%**

**Team 3**

Mercury is small

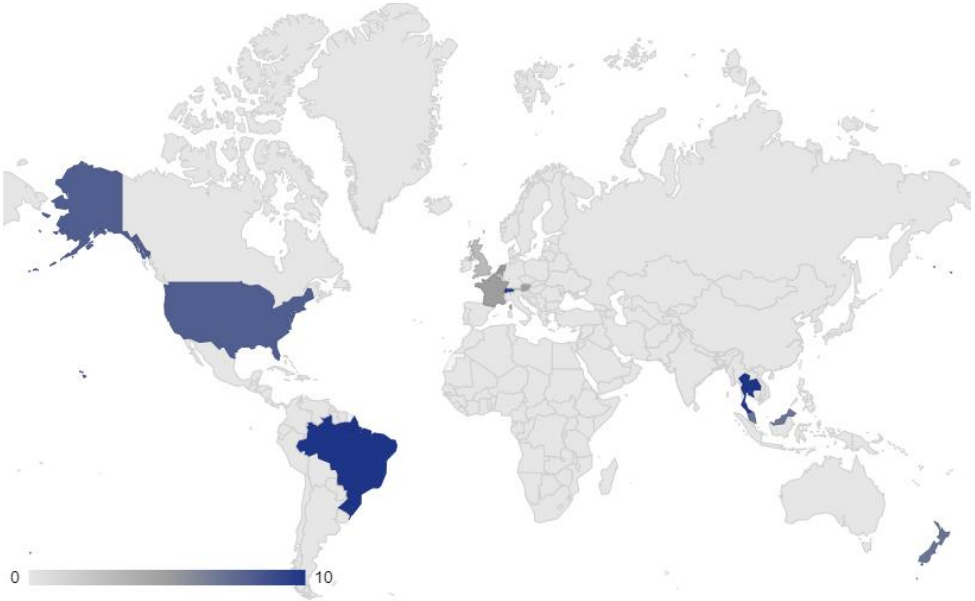
**15%**

**Team 4**

Earth has life

Follow the link in the graph to modify its data and then paste the new one here. **For more info, click here**

# Map




## Mercury

Mercury is the closest planet to the Sun and the smallest one in the entire Solar System. This planet’s name has nothing to do with the liquid metal, since Mercury was named after the Roman messenger god. Despite being closer to the Sun than Venus, its temperatures aren't as terribly hot as that planet’s

Follow the link in the map to modify its data and then paste the new one here. **For more info, click here**

# Table

| | Team A | Team B | Team C | Team D | Team E | Team F |
|---|---|---|---|---|---|---|
| **Mercury** | XX | XX | XX | XX | XX | XX |
| **Mars** | XX | XX | XX | XX | XX | XX |
| **Saturn** | XX | XX | XX | XX | XX | XX |
| **Venus** | XX | XX | XX | XX | XX | XX |
| **Jupiter** | XX | XX | XX | XX | XX | XX |
| **Earth** | XX | XX | XX | XX | XX | XX |
| **Moon** | XX | XX | XX | XX | XX | XX |

# Roadmap infographic

| Initiative | Objective | Jan | Feb | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct | Nov | Dec |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Venus is very hot | Venus has a beautiful name and is the second planet from the Sun | | | | | | | | | | | | |
| Earth has life | Earth is the beautiful planet on which humans live | | | | | | | | | | | | |
| Mars is very cold | Despite being red, Mars is actually a cold place | | | | | | | | | | | | |
| Jupiter is a gas giant | Jupiter is the biggest planet in the Solar System | | | | | | | | | | | | |
| Saturn has rings | Saturn is a gas giant and has several rings | | | | | | | | | | | | |
| Mercury is small | Mercury is the closest planet to the Sun and the smallest one | | | | | | | | | | | | |

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# Thanks!

## Do you have any questions?

laura.coffey@mu.ie

hannah.casey.2016@mumail.ie

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# Icon pack

# Alternative resources

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**Photos:**

- Children drawing together in the classroom
- Positive disabled worker together with manager at the office
- Woman teaching kids about planets
- Family with disables person in cutout paper inclusion concept
- Hand drawn disabled child and friends
- Disabled child and friend top view
- Front view smiley girl and woman indoors
- Medium shot smiley girl painting
- Medium shot girls painting together
- Young woman doing speech therapy with kids

# Resources

Did you like the resources on this template? Get them for free at our other websites:

**Vectors:**

- Memphis cover collection

**Photos:**

- Medium shot kids painting indoors
- Kids looking through their new lesson
- Disabled child and friend high view
- Disabled child and friends drawn with pencils
- Inclusion word written in colourful chalk
- Drawing workshop with children with down syndrome
- Children playing with a wooden game
- Disabled worker filling papers for contract
- Young woman doing speech therapy with kids

**Icons:**

- Icon Pack: Learning | Lineal

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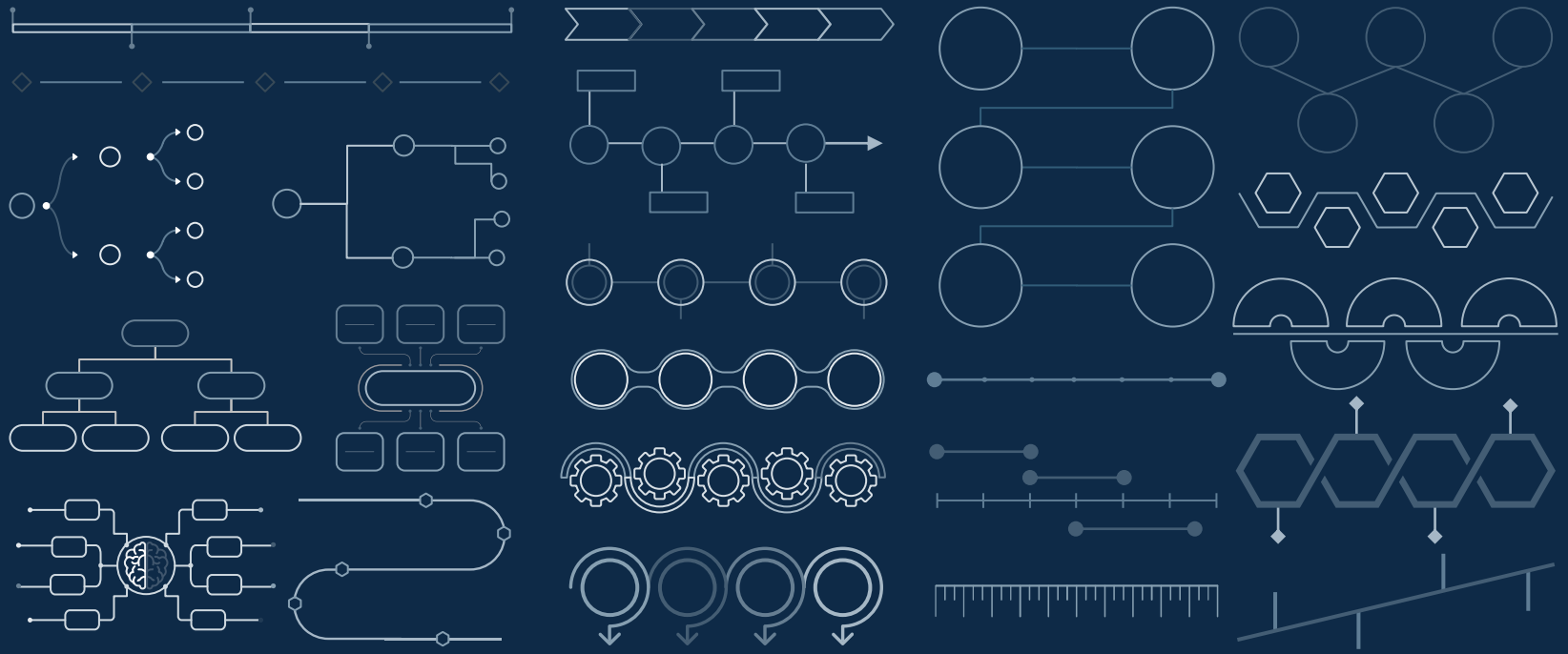

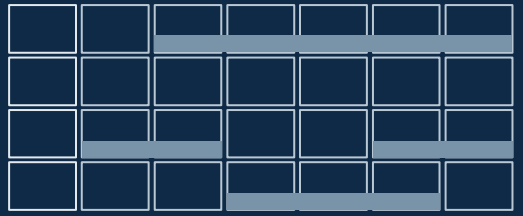

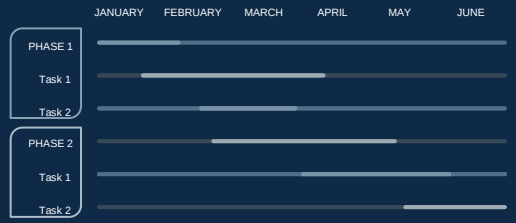
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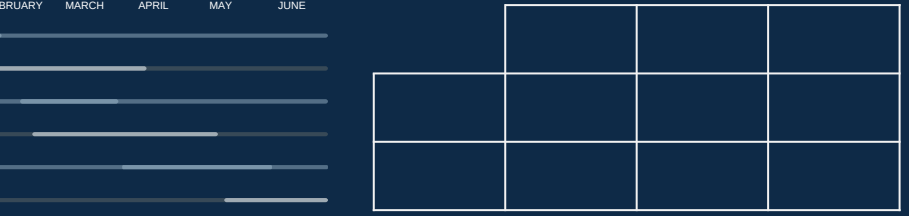

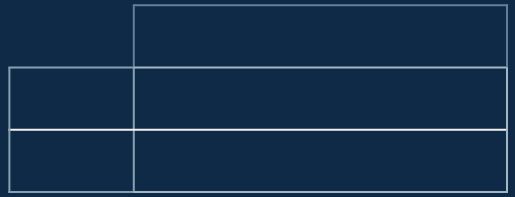

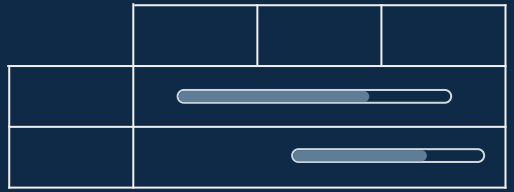

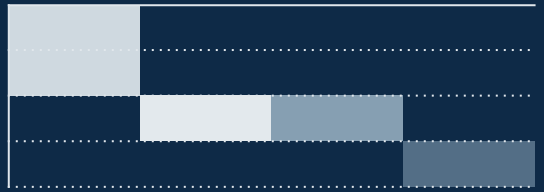

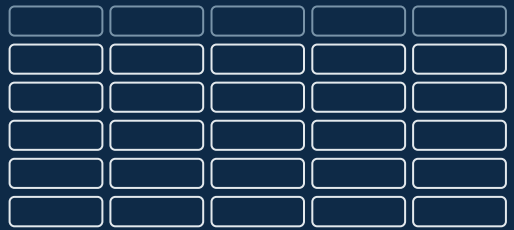

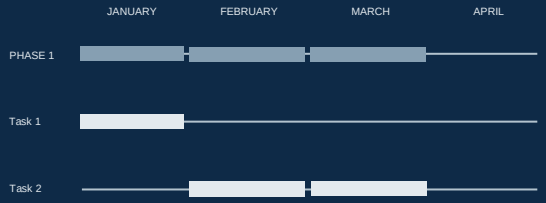
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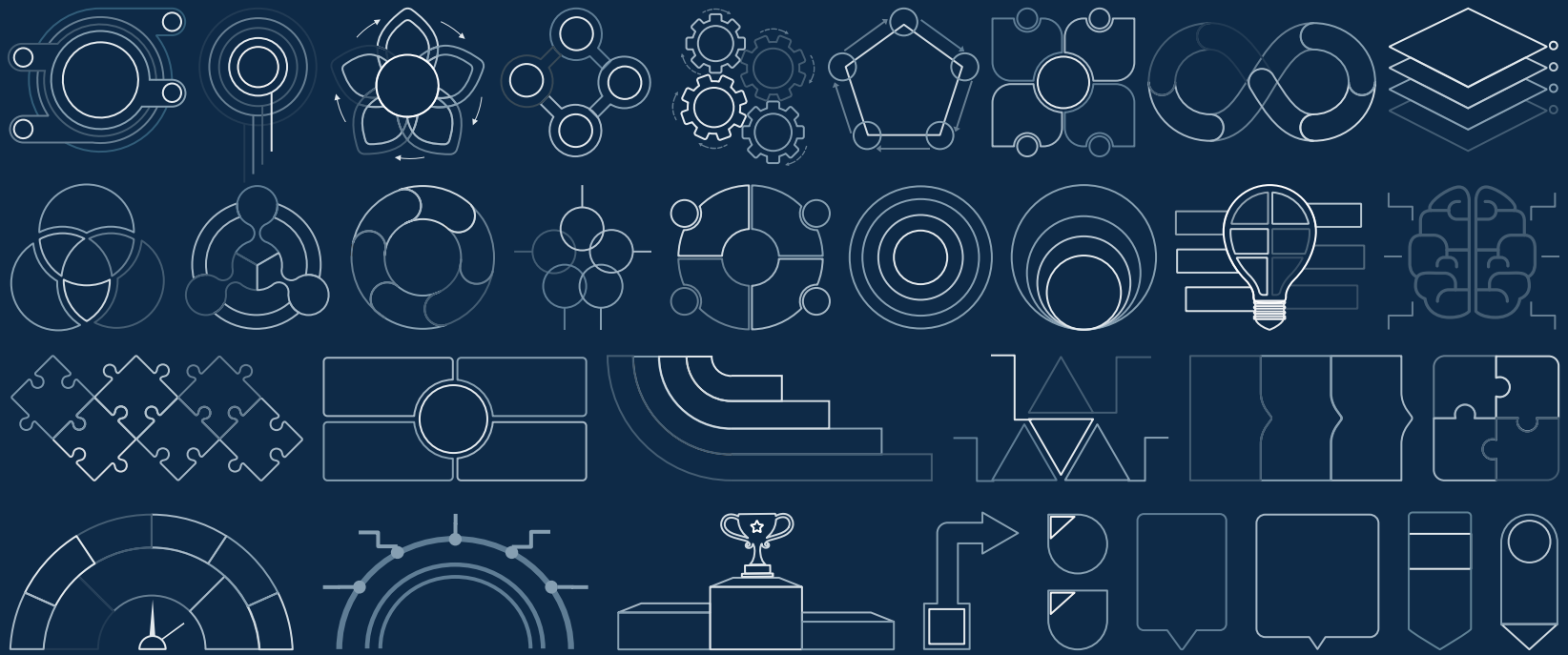

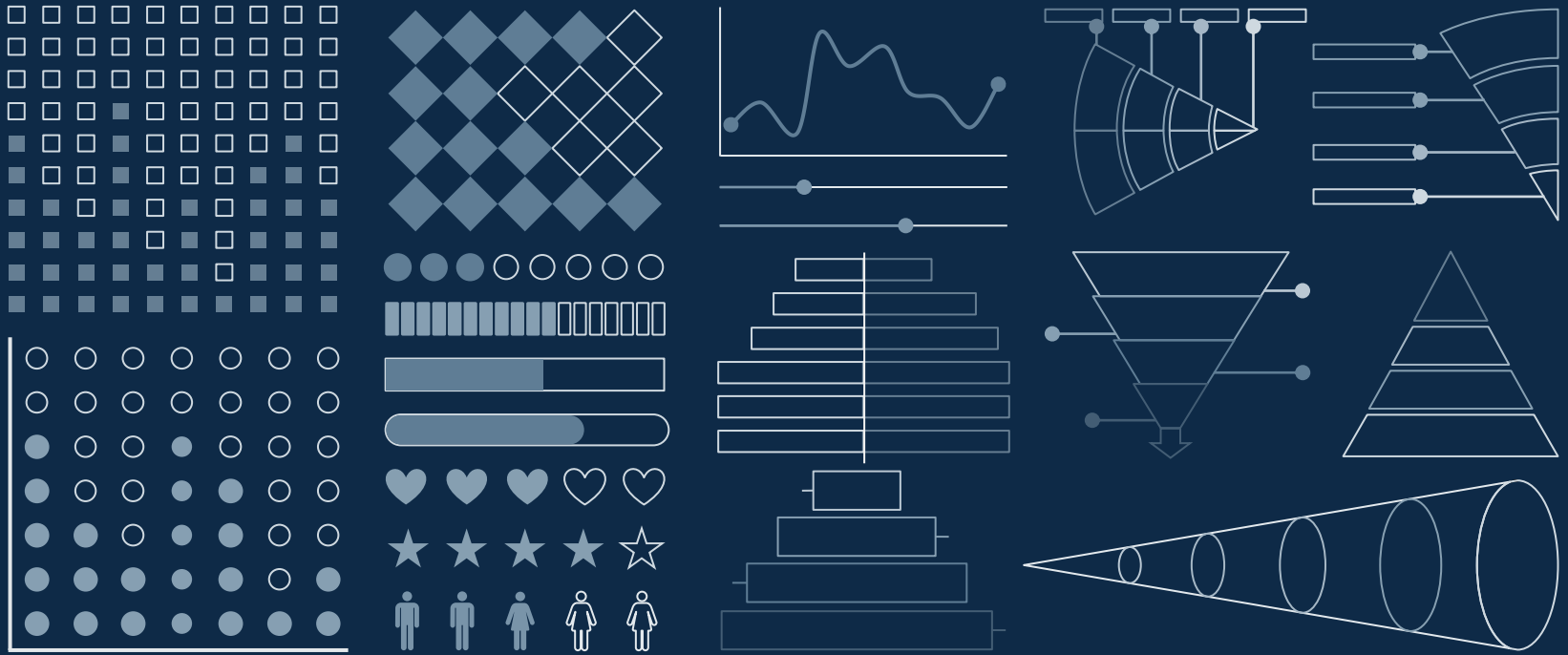

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