



**Isle of Man  
Government**

*Reiltys Ellan Vannin*




# Children with Complex Needs Service User Feedback

Care Pathways and Service Delivery Transformation Project

Health and Social Care Transformation Programme

December 2020



The independent health and social care review by Sir Jonathan Michael in 2019 concluded that our Island is well placed to become **a model of how to deliver a fully integrated health and care system**

The review concluded that we need to deliver:

- High-quality, efficient services
  - Proven best value
  - As locally as appropriate
- Timely provision of services, which are both accessible and integrated with other aspects of the system
  - A system that's both financially and clinically sustainable

Sir Jonathan Michael's report included a package of 26 recommendations to achieving a financially and clinically sustainable, high quality health and care system for the Isle of Man

**Tynwald has for the first time committed dedicated resource** – from financial to people – to work together to deliver on these recommendations with the Health and Care Transformation Programme

# Health & Social Care Transformation Programme

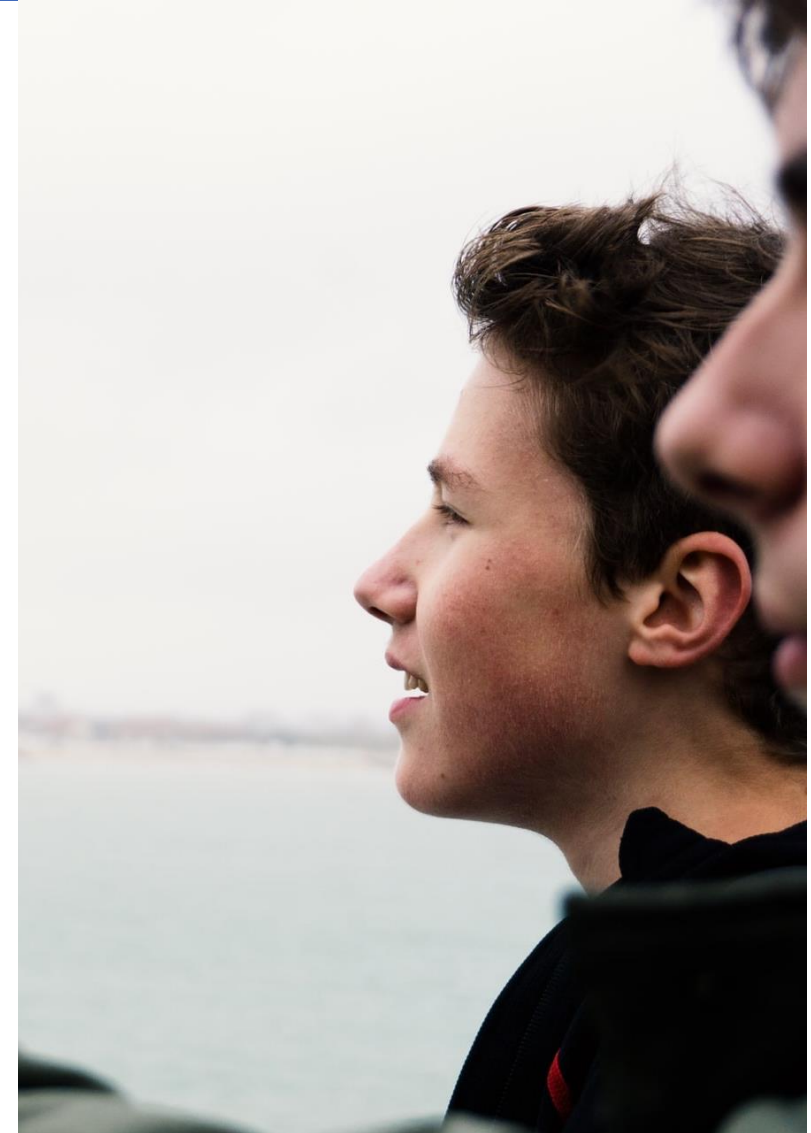
The Health and Care Transformation Programme is delivered by the Cabinet Office's Transformation Programme team in collaboration with the Department for Health and Social Care and Treasury (DHSC).

**Our role is to bring long term and systematic transformation to our health and care system**, in order to deliver high-quality, accessible and affordable health and social care services for every individual.

To achieve this, we:

- Engage with Service Users to ensure Service Users are at the heart of the improvement process
- Bring in colleagues from across the public service - particularly health and care professionals - to input, co-create and help us deliver our work
- Ensure that our focus on systematic change is aligned and working alongside other changes being delivered by the DHSC

**The Service User Feedback summarised in this pack has been gathered as part of the Care Pathways and Service Delivery Project (Pathfinders)**



# Care Pathways and Service Delivery Transformation (Pathfinders)

**This project will identify how we can improve the way services are delivered, now and in the future.**

The project takes a pathfinder approach and has three parts:

- Needs assessment\*
- Service-by-service review
- Integrated Care Pathway

The project team are starting with a focus on seven service areas:

- Diabetes
- Cardiovascular conditions
- Urgent and Emergency Integrated Care
- Cancer
- Eye Care
- Children with Complex Needs
- Autism

## Progress update:

- Stage 1: completed in August, this focused on desk-based research into Isle of Man needs for each service, reviewing best practice and developing an 'ideal' model
- Stage 2: through interviews, surveys and workshops we are gathering views on 'ideal' service and mapping out what is needed to achieve it
- We have held workshops with service users and their families/carers, service providers and health and care professionals. These will continue for the rest of 2020.

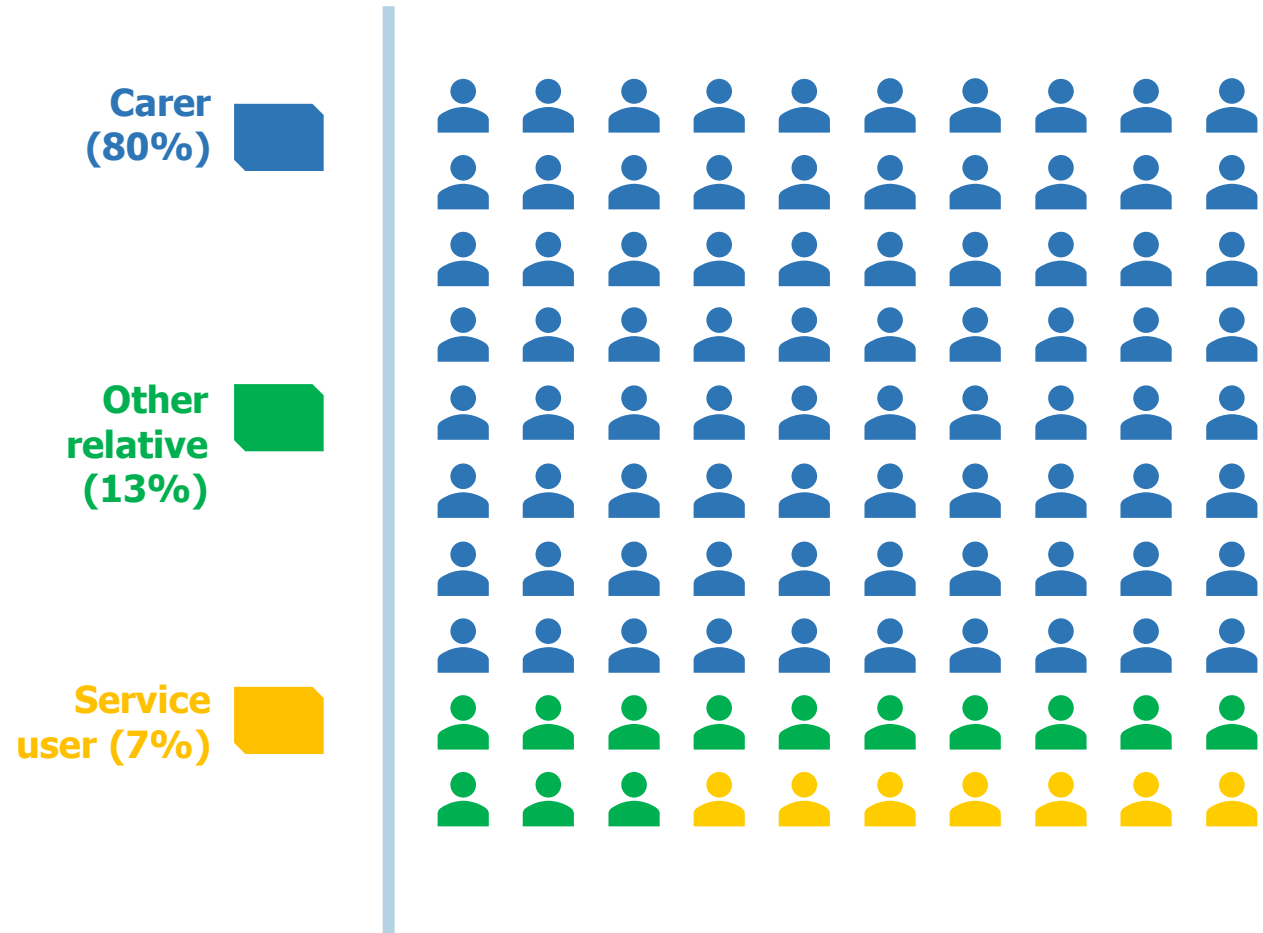
\*In September 2020, it was agreed that the Needs Assessment project would be reinstated as an independent project to Service-by-Service reviews to enable medium to long term needs assessments

# Service User Questionnaire Feedback



# CwCN service user feedback – demographics

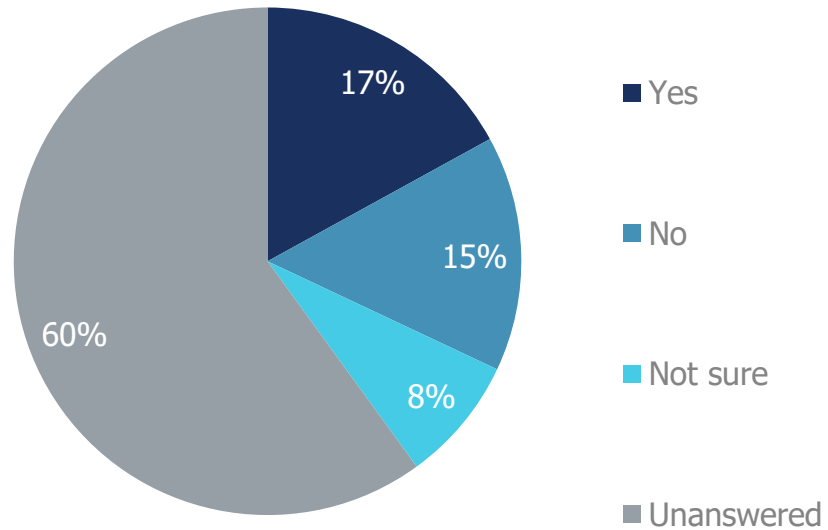
Out of **40** responses:



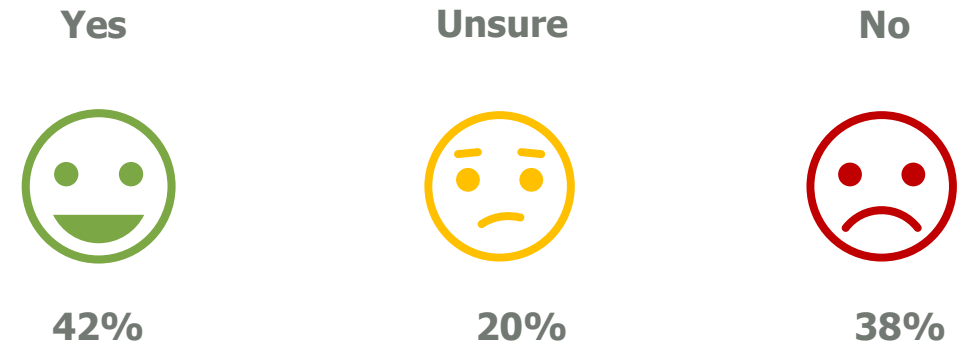
NB: percentages throughout the presentation may not add up to 100%, due to questions being left unanswered

# CwCN service user feedback

1. Do you have a care plan?

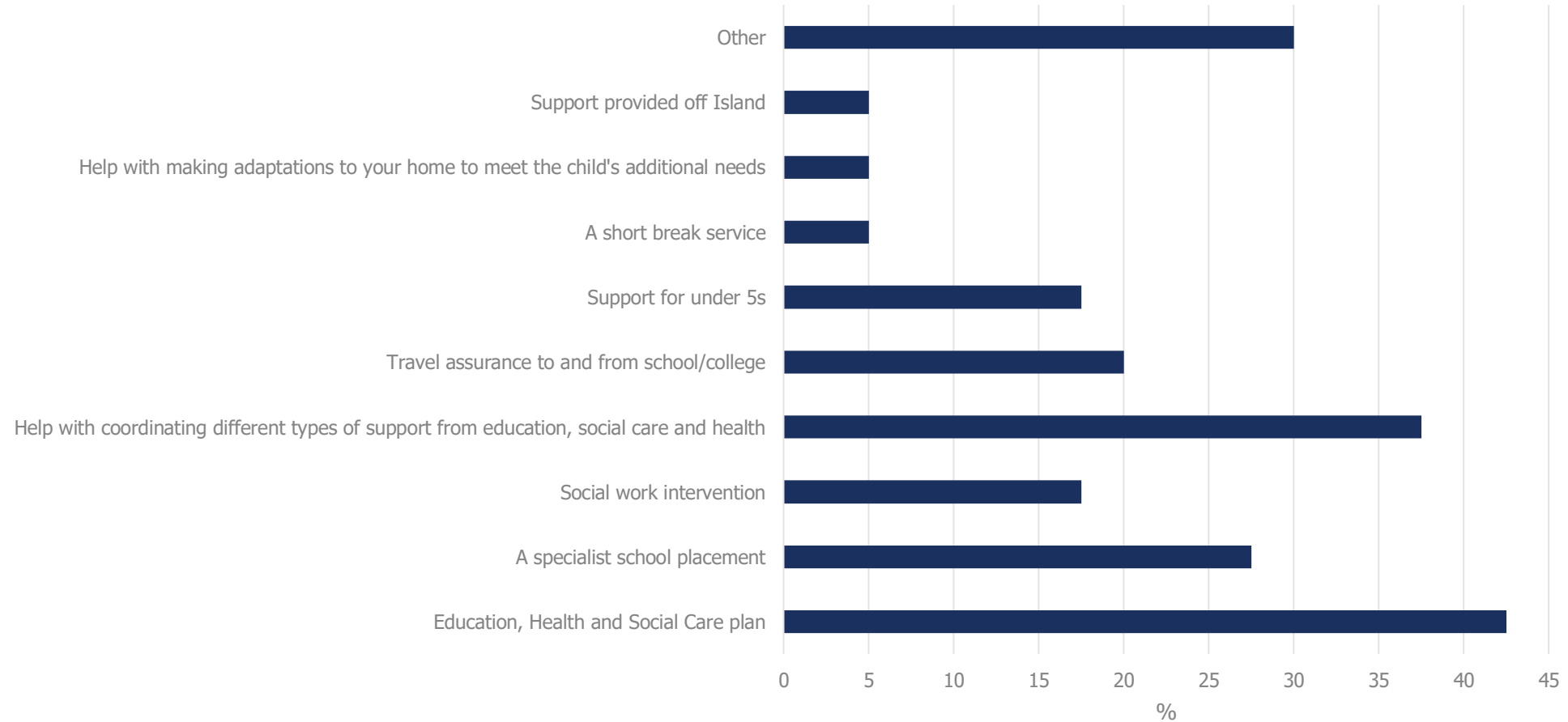


2. Were you happy with the level of involvement you or your carer had in developing your care plan?



# CwCN service user feedback

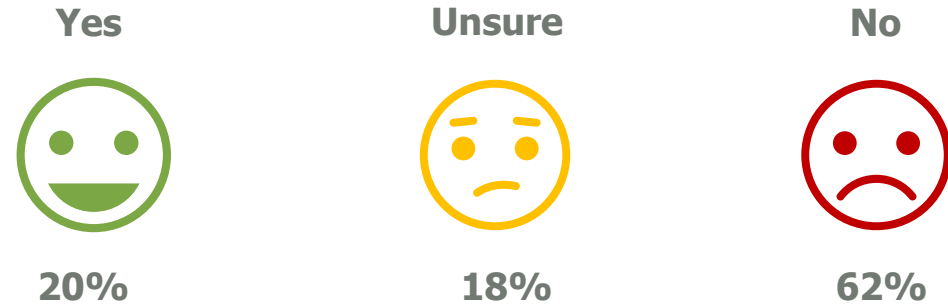
## 3. What does your care currently look like?



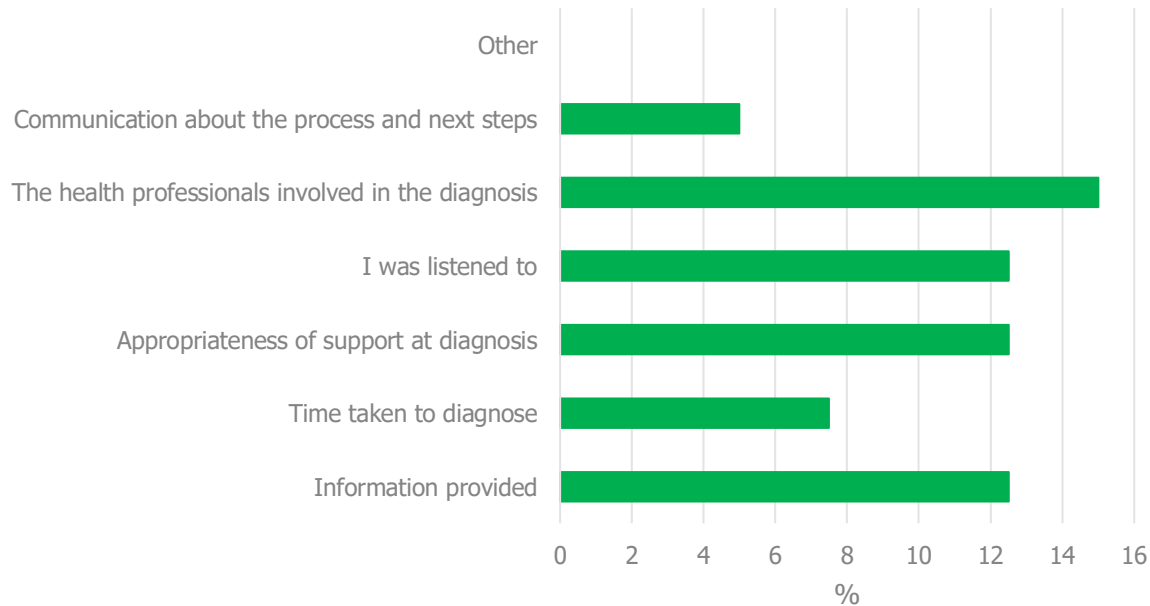


# CwCN service user feedback

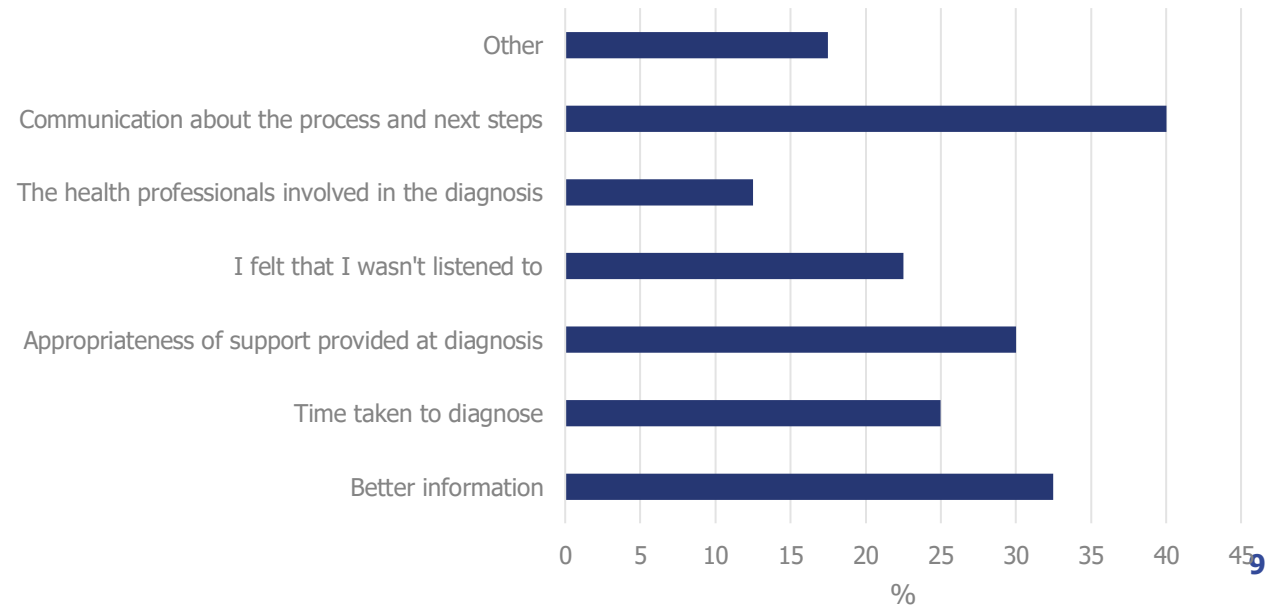
4. Were you satisfied with the level of care, information and support you received at diagnosis?



5. What were you happy with?

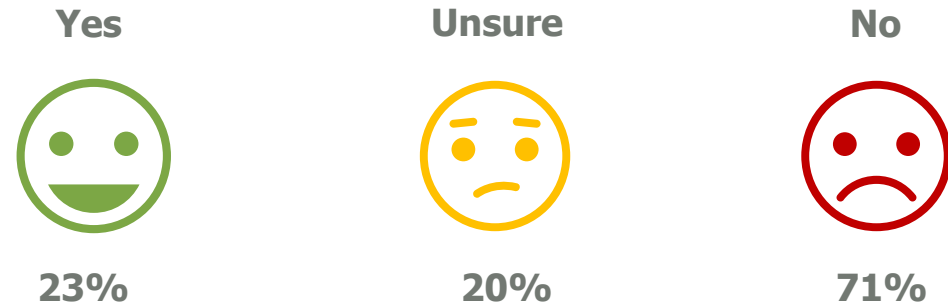


6. What was missing that would have been helpful?



# CwCN service user feedback

## 7. Are you satisfied with the level of care, information and support you receive now?



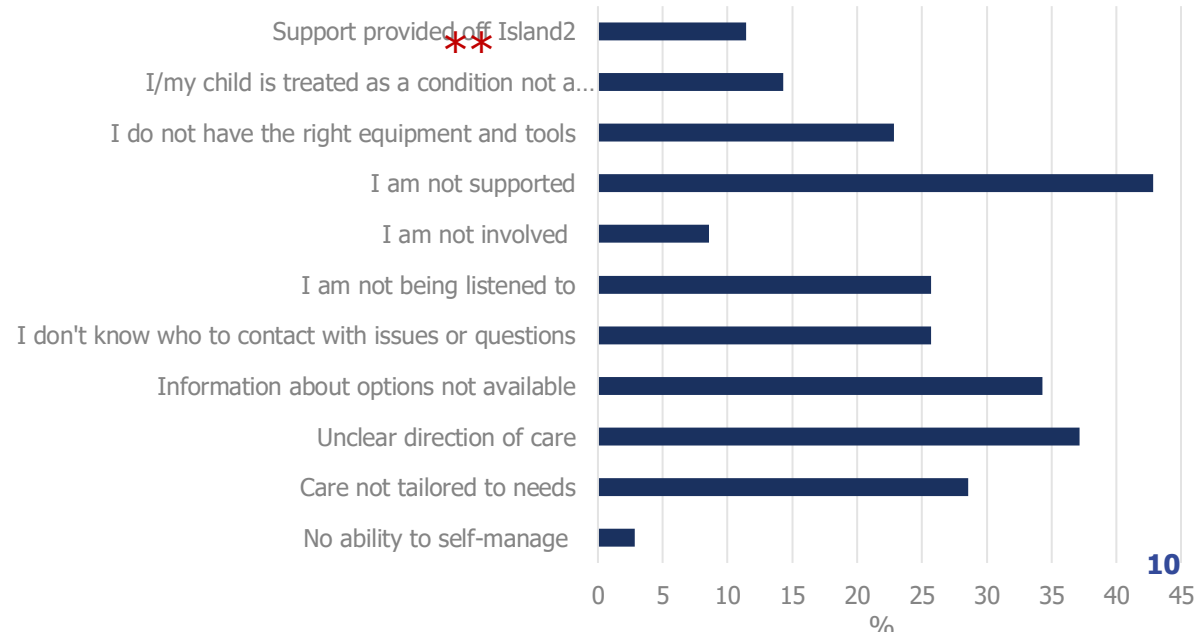
\*Treated as a child/young person rather than a condition

\*\*Treated as a condition rather than a child/young person

## 8. What are you happy with?



## 9. What is missing that would be helpful?



# CwCN service user feedback

11. If you have a healthcare plan, do you know what outcomes/goals you are trying to achieve?



Yes

**32%**



No

**38%**



Unsure

**30%**

12. Have you discussed transitioning to adult services with your key worker/any relevant professional?



Yes

**13%**



No

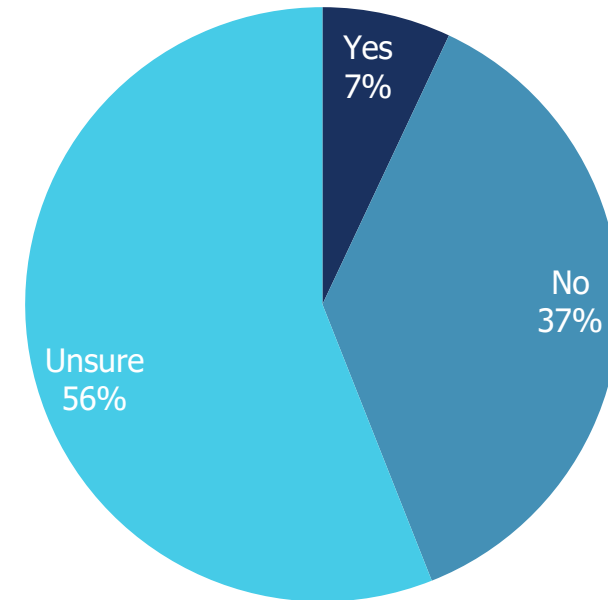
**31%**



Does not apply

**56%**

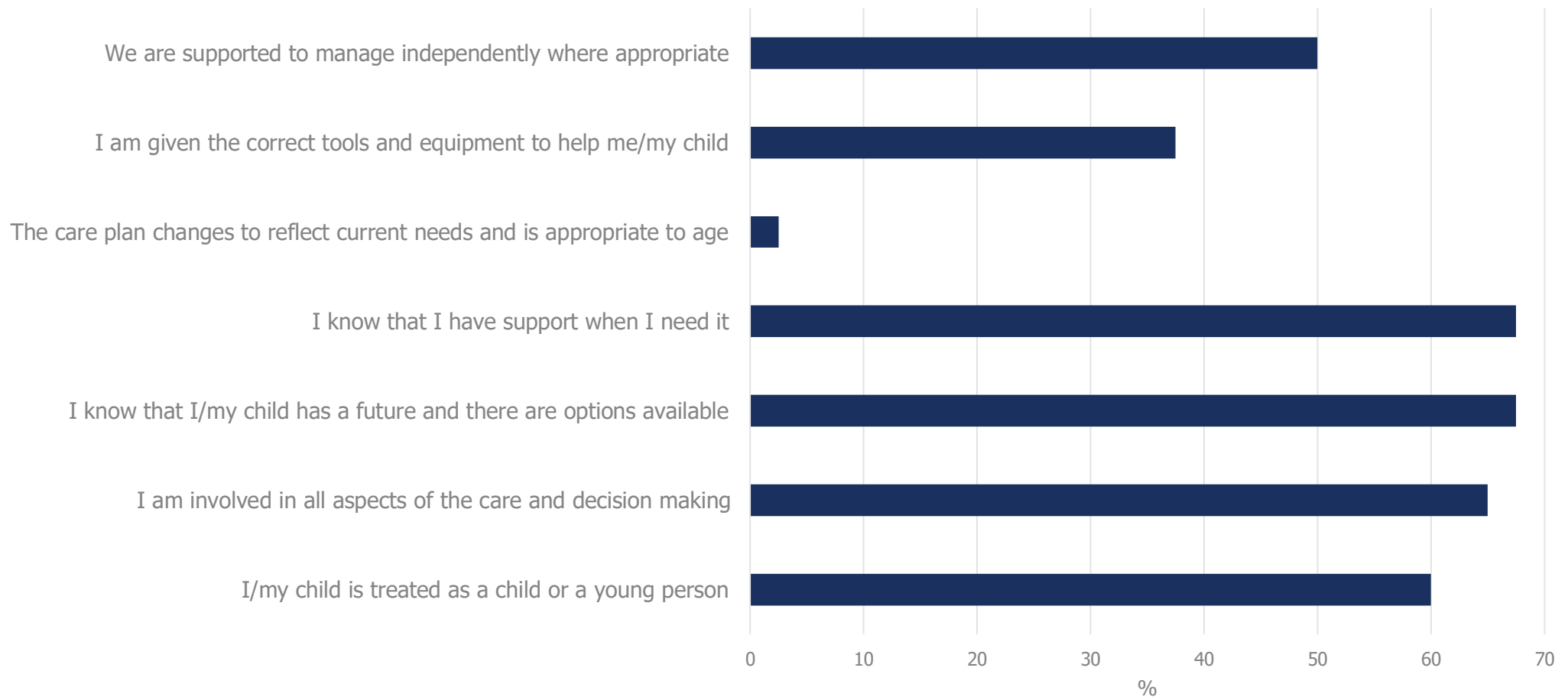
13. If applicable, were you satisfied with your transition to adult care services.



■ Yes ■ No ■ Unsure

# CwCN service user feedback

## 14. Which aspects of the care you receive are most important to you?



# CwCN service user feedback

Question 15: Are there any areas of the service you receive that you believe can be improved?

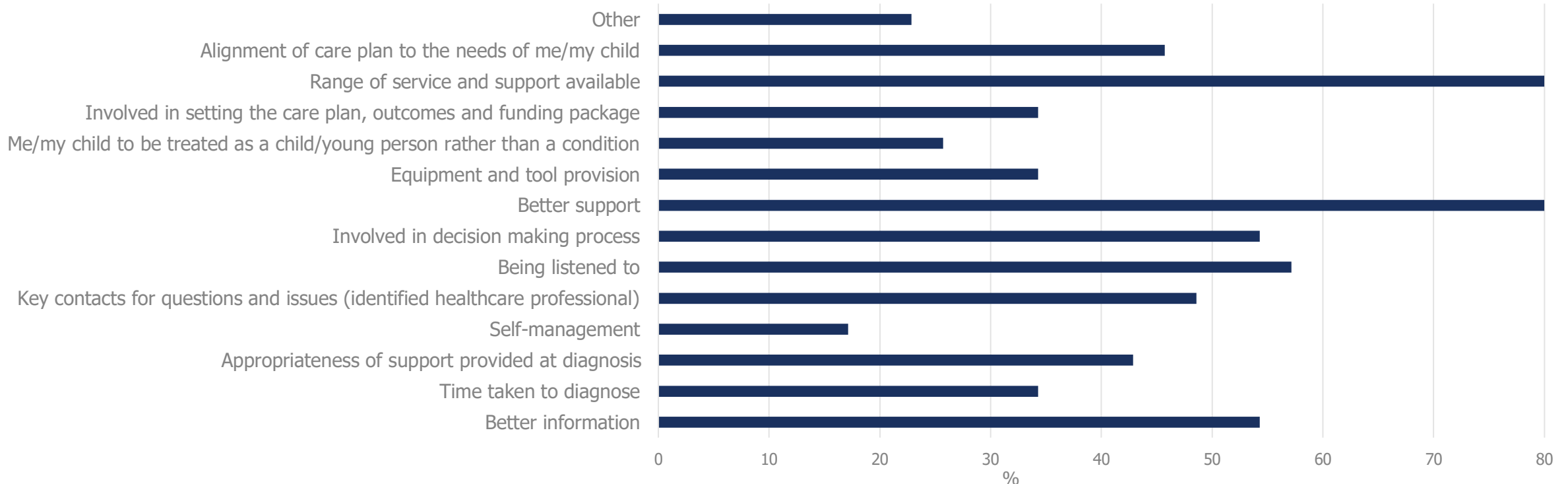


**Yes**  
**93%**



**No**  
**7%**

Question 16: If yes, please specify:



# Service User Interviews Feedback



## Service user interview - key themes

Lack of support at diagnosis

Delayed access to respite

Family and carers do not receive enough support and are left alone

No care coordinator on the Island

Children aren't recognised until it reaches crisis point

Poor transition to adult services

Not enough specialist staff at respite centres

Appropriate housing that would allow families remain close to their support system is difficult to find

No respite for children that are "too complex"

Poor treatment at Noble's

## Service user interview – what would service users like?

We have compiled key themes from the service user interviews and reports from Rebecca House and Crossroads.

To have fun and participate in activities with their peers

To only be grouped with other children/young people with similar needs and abilities

Timely access to help and support

Respite providers to have more training to meet different children's needs

Support at home

For their children to be treated as human beings and not just a condition/ a burden

To be listened to

More respite

A play area in the respite centre that is more sensory

Mental health support





# Next Steps

# What happens next

## Pathfinder Engagement Process



# We'd love to hear your thoughts...

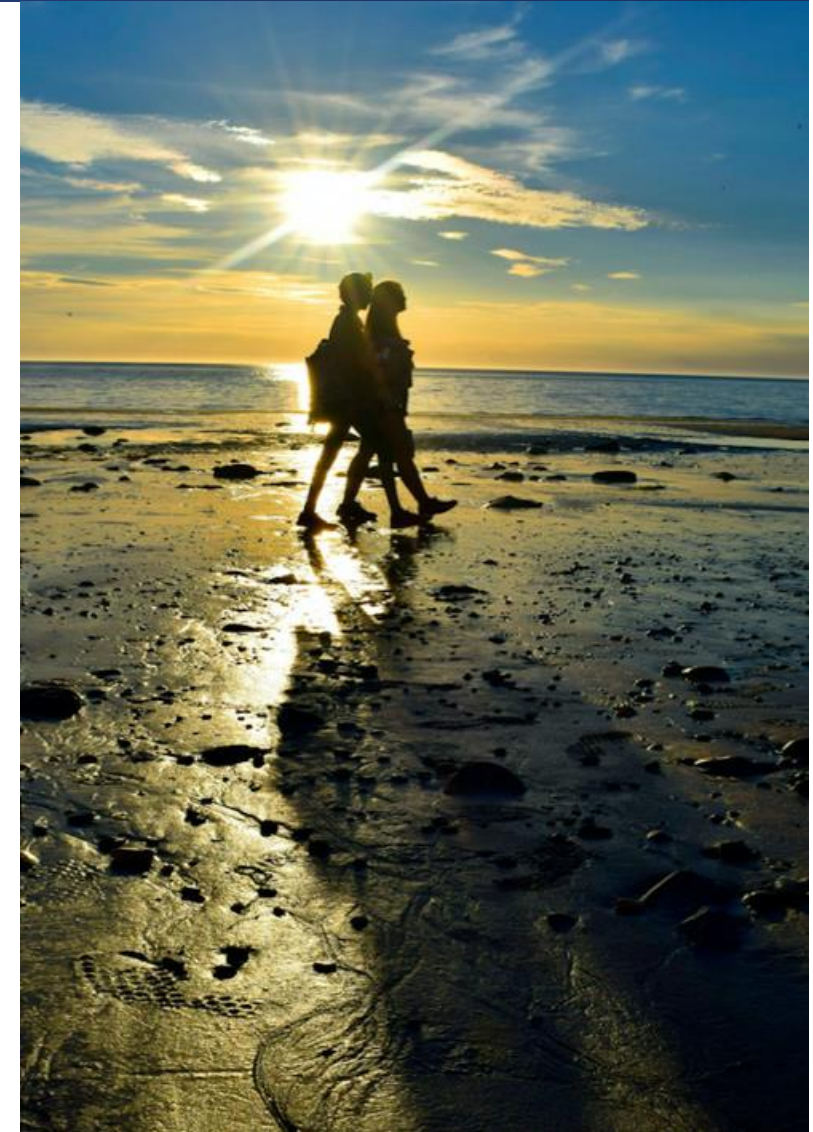
## Contacts:

### Health and Social Care Transformation Programme

- If you have any questions, comments or other feedback regarding the work being done to the Health and Social Care Transformation Programme team at:
  - [HealthandCareTransformation@gov.im](mailto:HealthandCareTransformation@gov.im)

### Care Pathways and Service Delivery (Pathfinders) Transformation Project

- If you have questions that are specific to the Care Pathways and Service Delivery Project (Pathfinders), including any related to the Pathfinder Engagement Process or the Service User Feedback findings summarised here, please contact one of our team:
  - Project Lead – Claire Bader
    - [claire.bader@gov.im](mailto:claire.bader@gov.im)
  - Project Manager – Francesca DeHaven
    - [francesca.dehaven@gov.im](mailto:francesca.dehaven@gov.im)



# Working together, we all want to create a sustainable system that:



improves quality of care



organises care around patient and service-user needs



delivers the right care, in the right place, at the right time, in the most affordable way

