

Testing the effectiveness of the Parents Plus Pathways programme for parents of adolescents with disabilities

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		<input type="checkbox"/> Protocol
Registration date 06/05/2020	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan
		<input type="checkbox"/> Results
Last Edited 06/05/2020	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data
		<input type="checkbox"/> Record updated in last year

Plain English summary of protocol

Background and study aims

Parents who have adolescents with intellectual disability often have additional needs and higher levels of stress. Despite this, there are no current parenting programmes specifically designed for this population. The aim of this study is to test whether a Parents Plus programme designed for these parents improves their adolescents' behavioural and emotional difficulties, improves their parenting and family adjustment and increases their parenting confidence and satisfaction. The researchers also hope to test whether it helps parents achieve the goals they have for themselves and their adolescent.

Who can participate?

Parents who have an adolescent with an intellectual disability who are linked in with participating Irish disability services

What does the study involve?

The study involves completing questionnaires on three different occasions and taking part in an eight-week parenting programme. Participants may be asked to complete the questionnaires twice before they do the programme, and once afterwards, or once before and twice afterwards.

What are the possible benefits and risks of participating?

The benefit of taking part is that parents may learn new skills and meet other parents who can help them meet their goals for their child and family. The risk is that this will not happen. There are no additional risks for completing the questionnaires, but it will take up some time.

Where is the study run from?

The study is being co-ordinated by Parents Plus and the School of Psychology, Trinity College Dublin (Ireland)

When is the study starting and how long is it expected to run for?

September 2018 to September 2020

Who is funding the study?
Parents Plus (Ireland)

Who is the main contact?

1. John Sharry
John@parentsplus.ie
2. Charlotte Wilson
cewilson@tcd.ie

Contact information

Type(s)

Public

Contact name

Dr John Sharry

Contact details

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Type(s)

Scientific

Contact name

Dr Charlotte Wilson

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Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

Nil known

Study information

Scientific Title

Parents Plus Pathways programme: a pragmatic randomised controlled trial

Study objectives

The Parents Plus Pathways Programme will positively impact parenting behaviour, adolescent behaviour, parenting satisfaction and confidence, and parents will meet their personally set goals compared to a waitlist control group.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 10/06/2019, Trinity College Dublin School of Psychology ethics committee (School of Psychology, Trinity College Dublin, Dublin 2, Ireland; +353 (0)1 896 3907; psycheth@tcd.ie), ref: SPREC042019-01

Study design

Wait-list randomised controlled trial

Primary study design

Interventional

Secondary study design

Randomised controlled trial

Study setting(s)

Other

Study type(s)

Treatment

Participant information sheet

Not available in web format, please use contact details to request a participant information sheet.

Health condition(s) or problem(s) studied

Behavioural and emotional difficulties

Interventions

Wait-list randomised controlled trial with a 3-month follow-up period for the intervention group. Disability services that registered to complete the training in the intervention were randomised to an immediate intervention group and a waitlist control group. No masking or blinding was possible. The randomisation was completed by a researcher who had no knowledge of the services involved. The study was facilitated centrally through Parents Plus and Trinity College Dublin, but the intervention took place in 24 different sites.

The intervention being tested is the Parents Plus Pathways Programme for parents of adolescents with intellectual or developmental disabilities. This is an 8-week group programme. It covers strategies for managing behaviour in adolescents with intellectual and developmental disabilities through positive parenting strategies, and strategies for managing being a parent in that context. Each group session is 1.5 hours long and covers a strategy for managing adolescent behaviour and a strategy for managing as a parent.

The control group was a waitlist group who were offered the group after the intervention group programme ended.

Intervention Type

Behavioural

Primary outcome measure

1. Problem behaviours, prosocial behaviours, and emotional difficulties measured using the CAPES (Child Adjustment and Parental Efficacy Scale)
2. Parenting behaviours and family adjustment measured using the PAFAS (Parent and Family Adjustment Scale)

Measured at pre-intervention, post-intervention and 3-month follow up for intervention group, and at baseline and two months later (pre-intervention) and two months following this (post-intervention) for waitlist-control group

Secondary outcome measures

1. Parental self-efficacy measured using the CAPES
2. Parental satisfaction measured using the Kansas Satisfaction Scale
3. Parent goals for self and parent goals for child measured using the Parents Plus goal setting procedure

Measured at pre-intervention, post-intervention and 3 month follow up for intervention group, and at baseline and 2 months later (pre-intervention) and 2 months following this (post-intervention) for waitlist-control group.

Overall study start date

01/09/2018

Completion date

01/09/2020

Eligibility

Key inclusion criteria

There were two types of inclusion criteria. Parents who were eligible to take part were determined by each service. The researchers instructed services that the programme was for

parents of adolescents with intellectual or developmental disabilities. However, as it was a pragmatic trial they left it up to services to determine individual eligibility. They would suggest that it was:

1. A parent of an adolescent (aged 12-20) with an intellectual or developmental disability
2. A parent who is willing and able to attend 8 group sessions

Service inclusion criteria included:

1. A service whose clients were children, adolescents and/or young adults with intellectual disabilities and/or developmental disabilities
2. A service who had two practitioners who could attend training
3. A service who was willing to take part in the evaluation and request and collect data from parents

Participant type(s)

Carer

Age group

Adult

Sex

Both

Target number of participants

24 services expressed an interest. Each service was required to run one group. Each group was ideally between 5 and 12 participants. This would lead to a sample size of between 120 and 288. This was sufficient to find a small effect size.

Key exclusion criteria

There were no official exclusion criteria. Each service was requested to invite suitable participants and therefore the exclusion criteria were left up to individual services.

Date of first enrolment

18/06/2019

Date of final enrolment

20/01/2020

Locations

Countries of recruitment

Ireland

Northern Ireland

United Kingdom

Study participating centre

Brothers of Charity, Galway

Woodlands Centre, Renmore

Galway
Ireland
H91 KN20

Study participating centre
Brothers of Charity, Ballincollig
Positive Behavioural Support Services
Chapel Gate
Ballincollig
Cork
Ireland
P31 EP26

Study participating centre
West Cork Child Development Service
St Mary's Road,
Dunmanway
Cork
Ireland
P47 PD89

Study participating centre
St Paul's Special School, Beaumont
Beaumont Woods,
Beaumont
Dublin 9
Dublin
Ireland
D09 VY30

Study participating centre
Down Syndrome Ireland, Ballymount
Unit 3, Park Way House
Western Parkway Business Park
Ballymount Drive,
Dublin 12
Dublin
Ireland
D12 HP70

Study participating centre

Down Syndrome Centre, Cabinteely

Shrewsbury House
Old Bray Road
Cabinteely
Dublin 18
Dublin
Ireland
D18 KX60

Study participating centre

CAMHS ID

Skehard Road
Cork
Ireland
T12 YR2P

Study participating centre

Treetops Children's Services

Cork Street
Dublin 8
Dublin
Ireland
D08 DH31

Study participating centre

Daughters of Charity

23 Ashtown Road
Navan Road
Dublin 7
Dublin
Ireland
D07 E4EK

Study participating centre

Cheeverstown House

Templeogue Road
Dublin 6
Dublin
Ireland
D6W TX36

Study participating centre
South Kildare Network Disability Team
Cill Dara Primary Healthcare Campus
Curragh Road
Kildare
Ireland
R51 RX51

Study participating centre
School Age Disability Team
Rossecourt Resource Centre
Balgaddy
Lucan
Co Dublin
Ireland
K78 R9C9

Study participating centre
Child Development Team
Bailis Resource Centre
Johnstown
Co. Meath
Navan
Ireland
C15 W303

Study participating centre
COPE Foundation
Bonnington
Middle Glanmire Road
Montenotte
Cork
Ireland
T23 PT93

Study participating centre
Ability West
Blackrock House
Dún Na Carraige
Blackrock
Salthill

Galway
Ireland
H91 R254

Study participating centre
Scoil Chiaráin Special School
Saint Canice's Road
Dublin 11
Dublin
Ireland
D11 VK64

Study participating centre
Stewarts Care
Mill Lane
Palmerstown
Dublin 20
Dublin
Ireland
D20 DV79

Study participating centre
Children's Services Centre,
Kilcreene Hospital Complex
Ballycallan Road
Kilkenny
Ireland
R95 DK07

Study participating centre
Beechpark Disability Service
Beechpark Service
Bryan S. Ryan Building
Main Road
Tallaght
Dublin
Ireland
D24 HH7F

Study participating centre

Children's Early Intervention Service

Northern Health & Social Care Trust Headquarters
Bretten Hall
Bush Road
Antrim
Belfast
United Kingdom
BT41 2RL

Study participating centre**West Limerick Children's Services**

28 Oak Park
Newcastle West
Limerick
Ireland
V42 E248

Study participating centre**Letterkenny Youth and Family Service**

New Line House
Glencar
Letterkenny
Ireland
F92 CDC0

Study participating centre**Donegal Down Syndrome Centre**

4 Garda Terrace
High Road
Letterkenny
Ireland
F92 TX3X

Sponsor information

Organisation

Parents Plus

Sponsor details

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Eccles Street

Dublin
Ireland
D07 R2WY
+353 (0)1 854 5185
info@parentsplus.ie

Sponsor type

Charity

Website

<https://www.parentsplus.ie>

Funder(s)

Funder type

Charity

Funder Name

Parents Plus

Results and Publications

Publication and dissemination plan

The researchers intend to submit a paper with the main results in May 2020. They intend to publish final results (including the impact of the intervention on the waitlist control group in Autumn 2020.

Intention to publish date

11/05/2020

Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study are/will be available upon request from Charlotte Wilson (cewilson@tcd.ie). Data files with fully anonymised data, both raw data and subscales for each measure (CAPES, PAFAS, KSS, Goals) along with some basic demographic data (age of child and parent, gender of child and parent, number of children with disabilities in the family, diagnoses) will be available from Summer 2021 for at least 10 years (indefinitely if it is possible to formally archive). Data will be made available to researchers who have ethical approval to conduct studies that are in line with the original aims of the study. Consent from participants has been given for this, and none of the data will be identifiable.

IPD sharing plan summary

Available on request