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

Submission date
29/04/2020

Recruitment status
No longer recruiting

Registration date
06/05/2020

Overall study status
Completed

Last Edited
06/05/2020

Condition category
Mental and Behavioural Disorders

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] 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
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2. Charlotte Wilson
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Contact information

Type(s)
Public

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Type(s)
Scientific

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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

Primary study design
Interventional

Study design
Wait-list randomised controlled trial

Study type(s)
Treatment

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(s)

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

Key secondary outcome(s)
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.

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

Healthy volunteers allowed
No

Age group
Adult

Sex
All

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
United Kingdom

Northern Ireland

Ireland

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
Templelogue 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

Funder(s)

Funder type
Charity

Funder Name
Parents Plus

Results and Publications

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