



Interventions on Psychological Well-being of Parents having Children with ASD: Insights from a Systematic Review

Unpublished findings. Should you wish to quote any of the findings, please contact Dr. Paul Wong at paulw@hku.hk

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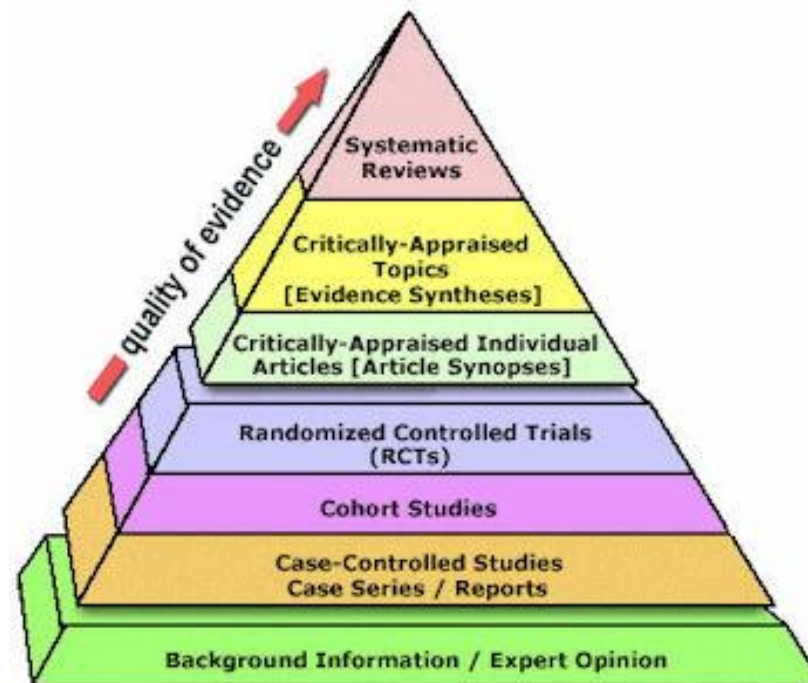
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Systematic Review

Levels of evidence pyramid



Aims

1. Present **findings** from the systematic review
2. Highlight the **importance** and **effective intervention elements** on psychological well-being of parents having children with Autism Spectrum Disorder (ASD)
3. Discuss **implications** for practice and research



Outline

1. Background

2. Method

3. Results

4. Our observations

5. Implications



1. Background



Background

1. Rising prevalence of **ASD** in global and local context
2. Emerging concerns on **parents' psychological well-being**
3. Limited **interventions for families** having children with ASD

Chan, K. S. (2016). *Survey: Most Parents of Children with Autism Report Discriminatory Experiences*. The Education University of Hong Kong.

Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). *Understanding Hong Kong Chinese Families' Experiences of an Autism/ASD Diagnosis*. *Journal of Autism and Developmental Disorders*, 46(4), 1164-1183.



2016年3月31日

教院調查：九成自閉症學童家長稱曾遭歧視
相關照片可於教院網頁下載：
<http://www.ied.edu.hk/web/news.php?qlang=tc>

香港教育學院（教院）調查發現，有近九成的受訪自閉症學童家長表示曾遭受不同程度的歧視，當中超過六成家長出現抑鬱症狀，影響心理健康。負責調查的學者建議社會須加強對自閉症的認識，並為病患學童的家庭提供更多支援。

調查由教院心理研究學系及幼兒教育學系於 2015 年 3 月至 12 月，以問卷形式進行，成功訪問了 424 名由 2 至 18 歲的自閉症學童家長，結果發現近九成受訪家長稱曾受到不同程度的歧視，當中有七成表示感到別人看不起自己，以及不願意與其交友。



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ORIGINAL PAPER

Understanding Hong Kong Chinese Families' Experiences of an Autism/ASD Diagnosis

Kathleen Tait¹ · Francis Fung² · Aihua Hu³ · Naomi Sweller⁴ · Wei Wang⁵

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Abstract Little is known about the experience of Chinese parents of children diagnosed with autism spectrum disorders (ASD) living in the Hong Kong Special Administrative Region. Seventy-five parents of children (aged 6 months–18 years) with ASD diagnoses completed the Family Quality of Life Scale. Forty-five parents from the original surveyed cohort, also participated in semi-structured interviews. Parents' perceptions of their child's disability were influenced both by their cultural background and by the limited and expensive, pre- and post-diagnostic services available. Longer waiting times to diagnosis were associated with lower emotional well-being and perceived disability-related support. Clinicians are encouraged to become part of the support network for parents of children with ASD, to help parents to adjust to caring for their child.

Keywords Parental information · Diagnosis · Autism spectrum disorder · Hong Kong SAR

Introduction



2. Objectives and research questions



2.1 Objectives

1. Summarize existing studies
2. Evaluate methodological quality
3. Synthesize major findings
4. Identify intervention elements



2.2 Research questions

1. What were the **methodological qualities** of the existing interventions for parents having children with ASD, targeting on their psychological well-being?
2. How were these interventions being **evaluated**?
3. What **outcomes** were reported on parents' psychological well-being?
4. What were the commonly used **intervention elements** among these studies?



3. Method



3.1 Established guideline for review

Protocol for systematic review

Built according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement (Mohor et al., 2015)

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*		
Section and topic	Item No	Checklist item
ADMINISTRATIVE INFORMATION		
Title:		
Identification	1a	Identify the report as a protocol of a systematic review
Update	1b	If the protocol is for an update of a previous systematic review, identify as such
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number
Authors:		
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors, provide physical mailing address of corresponding author
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
Support:		
Sources	5a	Indicate sources of financial or other support for the review
Sponsor	5b	Provide name for the review funder and/or sponsor
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
INTRODUCTION		
Rationale	6	Describe the rationale for the review in the context of what is already known
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
METHODS		
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
Study records:		
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review



PROSPERO registration at University of York
(Registration number: CRD42016039589)

3.2 Keywords & selection criteria

Combination of search terms

In 11 electronic databases

"autis*" OR "ASD"

AND

"parent*" OR
"family"

AND

"support*" OR "service*" OR "intervention*"

Selection Criteria

Inclusion criteria

1. Peer-reviewed journal articles
2. Full-text available
3. Written in English
4. Interventions for parents of children with ASD
5. With measurable outcomes

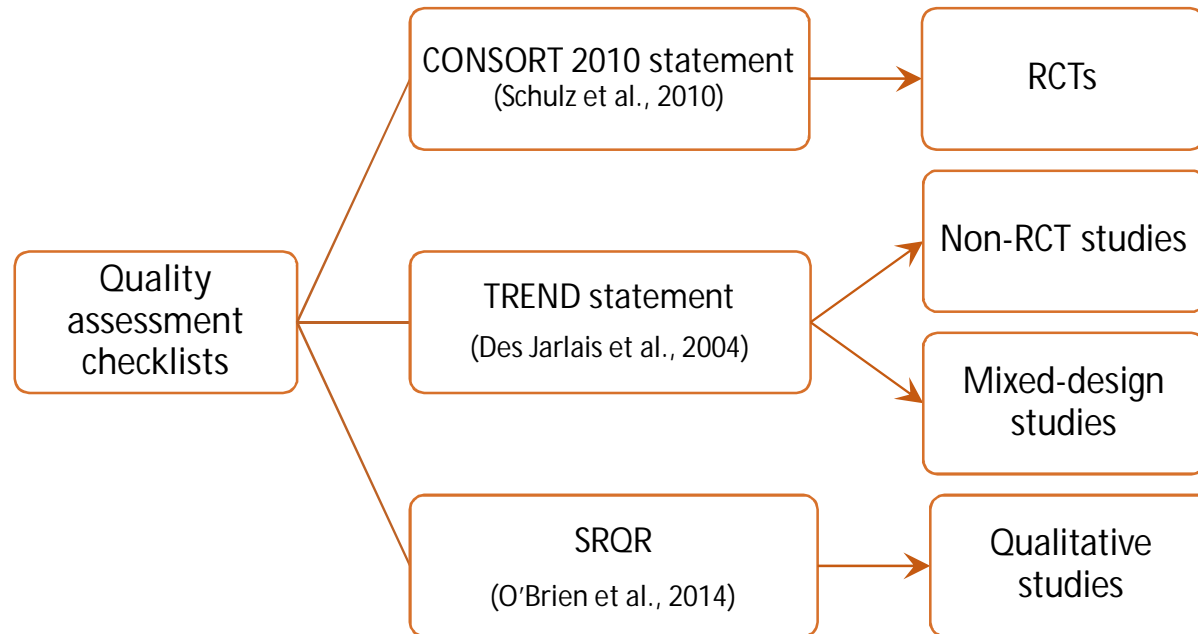
Exclusion criteria

1. Review/ systematic review articles
2. Letter or commentary paper
3. Non-intervention studies



3.3 Quality assessment & data analysis

Assessment on reporting quality



Data extraction and analysis method

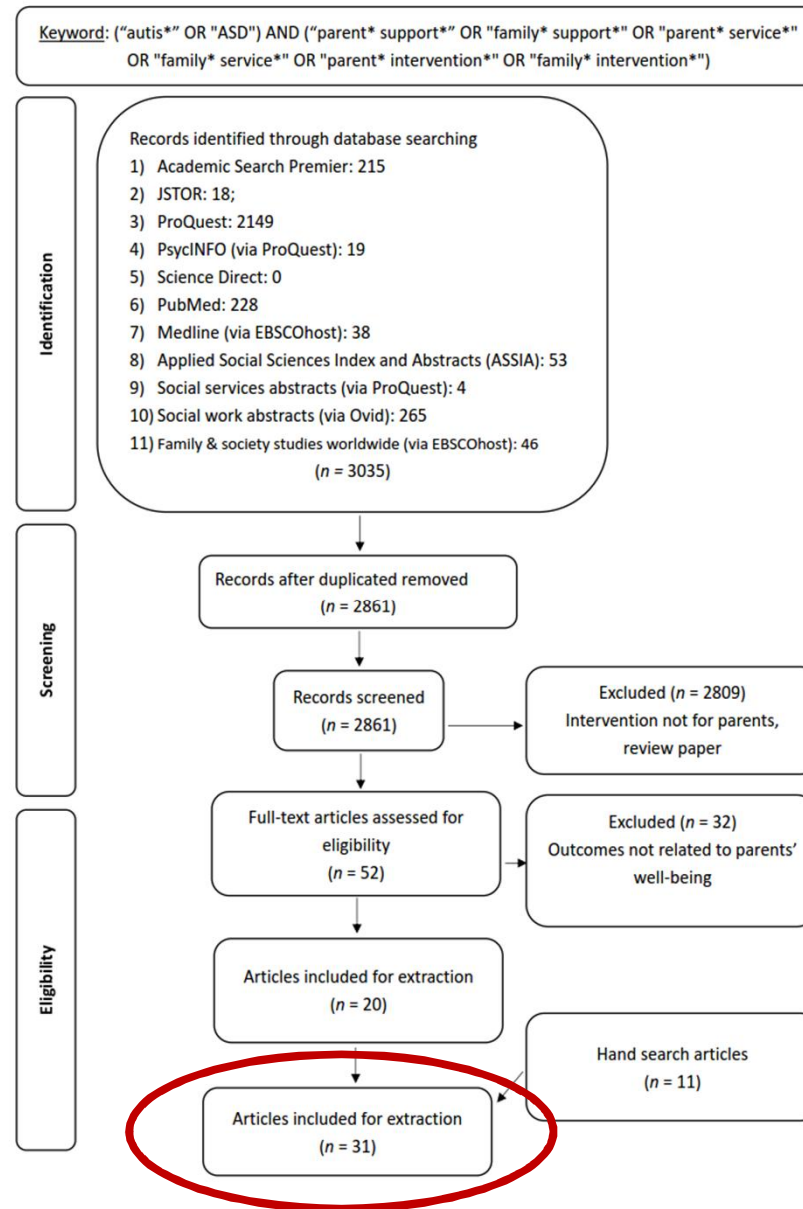
1. Two-phase convergent qualitative synthesis
2. Thematic synthesis



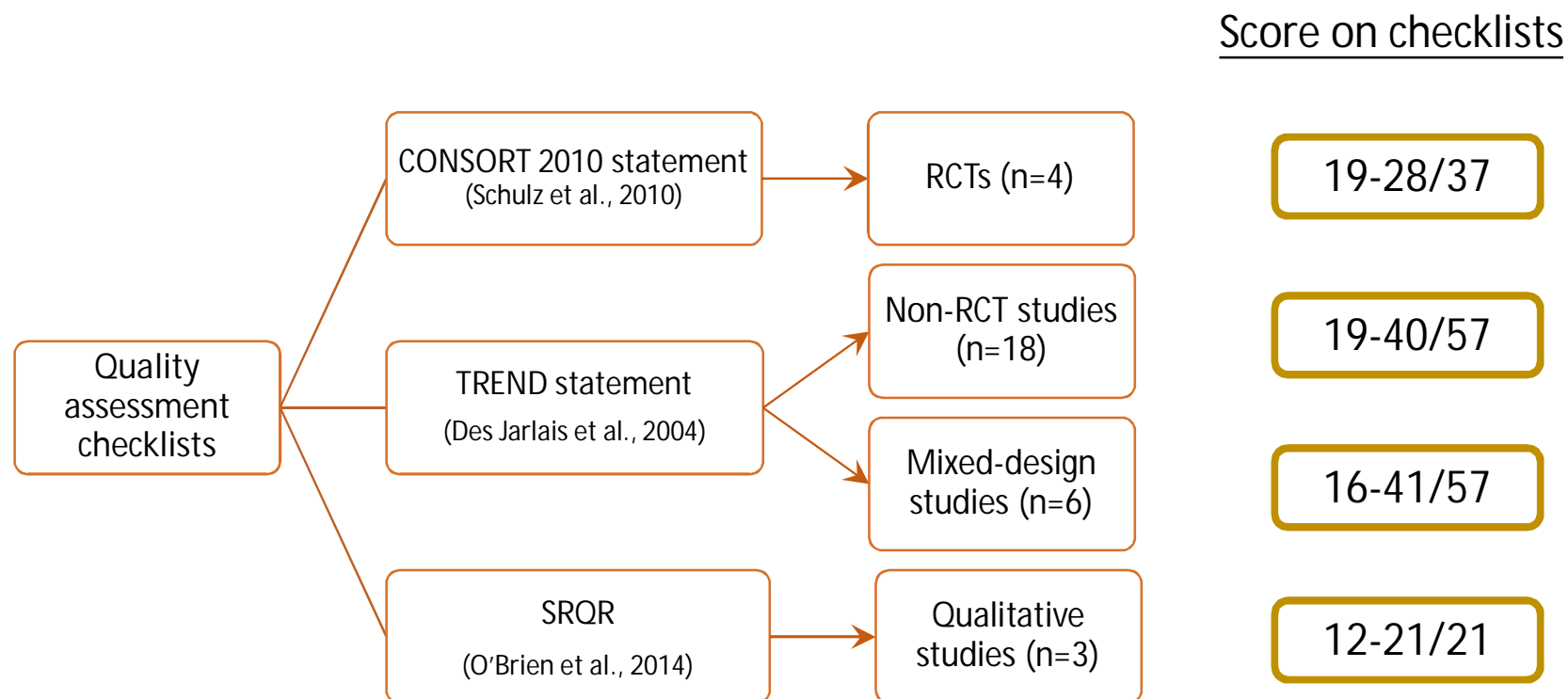
4. Results



4.1 Flow of study selection



4.2 Appraisal on reporting quality

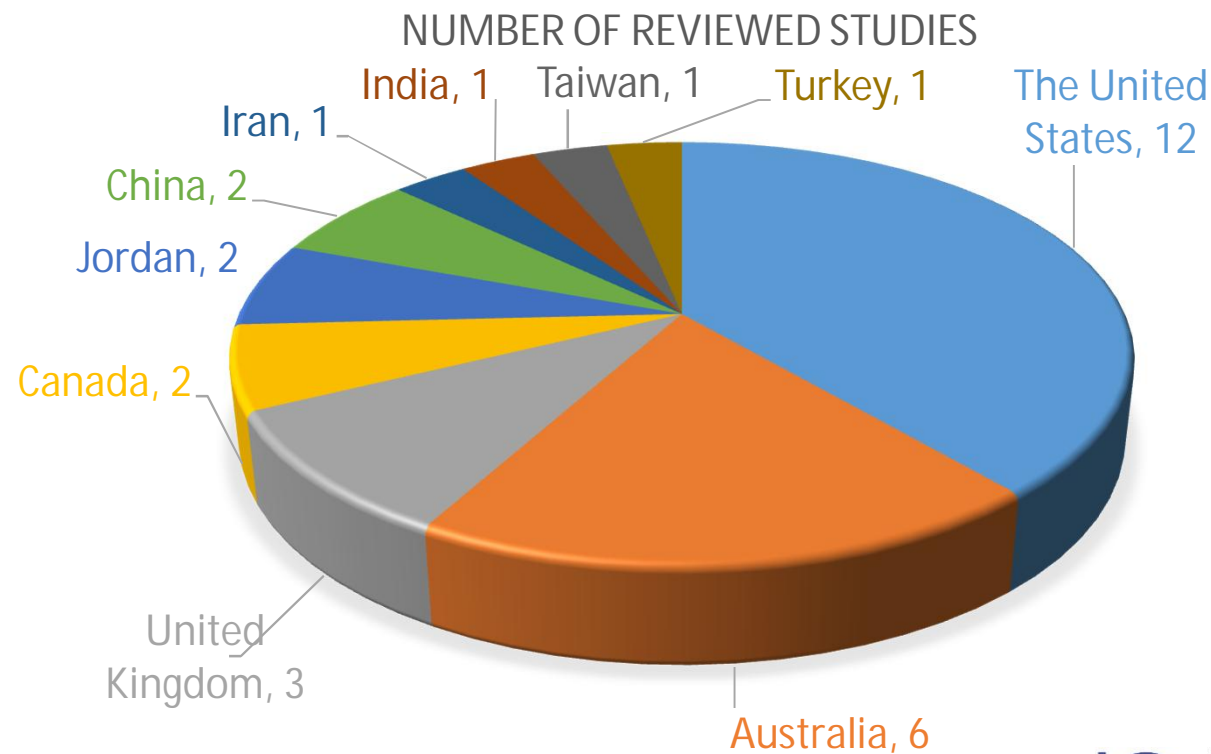


4.3 Description of studies (n=31)

1. Publication year

- 17 of them published within 2011-2016

2. Country



17



4.3 Description of studies - *Participants*

1. Total no. of participants included= 1,250
(mothers only, mother/father, couples, grandparents, or other caregivers)
2. **Sample size** varies from 3 to 122
3. Children in **different stages**



4.3 Description of studies – *Programme delivery*

According to the **National Institute for Clinical Excellence (NICE) guideline** (*National Institute for Clinical Excellence, 2006; Small et al., 2009*) and review studies on **parent education programmes** (*Lang et al., 2009; Dababnah & Parish, 2016*):

Group-based intervention	Intervention with established protocols	Intervention with fidelity check	Intervention with follow-up evaluation
n=17	n=18	n=7	n=10

Follow-ups vary from 1 month to 1 year



4.3 Description of studies – *Scope of measurements*

1. 39 different **measures** applied
2. 9 measure **domains** included

	Measure domain
1	Coping
2	General health
3	Family functioning
4	Parental perception
5	Self-efficacy
6	Quality of life
7	Positive affect
8	Distress
9	Psychological disturbance



4.4 Intervention effectiveness – *Positive qualities*

1. **Significant** improvements on positive qualities:

- a) Coping (n=7)
- b) Self-efficacy (n=7)
- c) General health (n=5)
- d) Family functioning (n=4)
- e) Parental perceptions (n=1)
- f) Quality of life (n=1)
- g) Affect (n=1)

2. **No significant** outcomes: 5 studies



4.4 Intervention effectiveness – *Negative qualities*

1. **Significant** reductions on negative qualities:

- a) Distress (n=15)
- b) Psychological disturbance (n=4)

2. **No significant** outcomes: 4 studies



4.5 Themes of intervention elements

All **28 effective** studies

Theme	Intervention element
ASD general information (n=11)	ASD knowledge (n=6)
	ASD information (n=5)
ASD-specific skill training (n=24)	Social communication intervention (n=5)
	Behavioral learning (n=4)
	Behavioral management (n=11)
	Problem-solving training (n=3)
	Cognitive behavioral intervention (n=1)
Parenting skill training (n=3)	Parenting intervention (n=3)
Parent psychological support (n=8)	Cognitive and emotional adjustment (n=1)
	Psychological support (n=4)
	Stress management (n=2)
	Mutual support (n=1)
Family leisure (n=1)	Family leisure (n=1)
Community understanding (n=2)	Public awareness (n=2)



4.5 Themes of intervention elements – *Age-specific 1*

1. Newly diagnosed group (n=4)

Theme	Intervention element
ASD general information (n=3)	ASD knowledge (n=1)
	ASD information (n=2)
ASD-specific skill training (n=3)	Social communication intervention (n=1)
	Problem-solving training (n=2)
Parent psychological support (n=1)	Mutual support (n=1)



4.5 Themes of intervention elements – *Age-specific 2*

2. Preschool group (n=6)

Theme	Intervention element
ASD general information (n=3)	ASD knowledge (n=2)
	ASD information (n=1)
ASD-specific skill training (n=9)	Social communication intervention (n=2)
	Behavioral learning (n=3)
	Behavioral management (n=3)
	Problem-solving training (n=1)
Parent psychological support (n=3)	Psychological support (n=1)
	Stress management (n=2)
Community understanding (n=1)	Public awareness (n=1)



4.5 Themes of intervention elements – *Age-specific 3*

3. Across age groups (n=6)

Theme	Intervention element
ASD general information (n=4)	ASD knowledge (n=2)
	ASD information (n=2)
ASD-specific skill training (n=2)	Behavioral management (n=1)
	Cognitive behavioral intervention (n=1)
Parent psychological support (n=1)	Psychological support (n=1)
Family leisure (n=1)	Family leisure (n=1)
Community understanding (n=2)	Public awareness (n=2)



4.5 Themes of intervention elements – *Mode of intervention 1*

1. Individual-based studies (n=9)

Theme	Intervention element
ASD-specific skill training (n=11)	Social communication intervention (n=2)
	Behavioral learning (n=4)
	Behavioral management (n=3)
	Problem-solving training (n=2)
Parenting skill training (n=2)	Parenting intervention (n=2)



4.5 Themes of intervention elements – *Mode of intervention 2*

2. Group-based studies

Theme	Intervention element
ASD general information (n=7)	ASD knowledge (n=4)
	ASD information (n=3)
ASD-specific skill training (n=11)	Social communication intervention (n=2)
	Behavioral management (n=7)
	Problem-solving training (n=1)
	Cognitive behavioral intervention (n=1)
Parenting skill training (n=3)	Parenting intervention (n=3)
Parent psychological support (n=6)	Cognitive and emotional adjustment (n=1)
	Psychological support (n=3)
	Stress management (n=1)
	Mutual support (n=1)
Family leisure (n=1)	Family leisure (n=1)
Community understanding (n=1)	Public awareness (n=1)



5. Observations



Observations

1. Growing attention on parent's psychological well-being
2. Various reporting quality and evidence level of interventions
3. Various sample size and characteristics
4. Heterogeneous outcomes on psychological well-being
5. Increasing intervention elements associated with positive psychological well-being qualities



6. Limitations



Limitations

1. Various **child's factors** (e.g. the severity of disorder, developmental stage, level of functioning)
2. Various **parent's factors** (e.g. individual demographic variables, socioeconomic status)
3. Review restricted to **English** publications



7. Implications



7.1 Implications – Theory & Research

Theory

1. Examine the adaptation of theory into practice
-> The Double ABCX model on **family stress**
2. Explore wider scope of theory on strength-based intervention
-> The Family Adjustment and Adaptation Response (FAAR) model on **family resilience**

Research

1. Develop **more rigorous studies** for evidence-based interventions
2. Encourage a **paradigm shift** from child-centred to family-centred support

The A-POWER family support framework



7.2 Implications – Practice & Policy

Practice

1. Understand **different intervention elements** for future service development
2. Develop **age-specific** and **gender-specific** interventions
3. Develop interventions for parents with **elder child**, according to the research and service cliff

Policy

1. Compare global and local **policy** (US, Australia, low-resource setting countries and Hong Kong) and interventions developed



8. Recommendations



Recommendations

1. Increase **attention** on interventions targeting parent's psychological well-being
 - > Cognitive Behavioral Therapy (CBT) parents groups
2. Develop more rigorous **research design** and better **reporting quality** of intervention outcomes
 - > Dissemination and sustainability of effective practices
3. Increase diversity on **intervention elements** for holistic family support
 - > Age-specific, gender-specific and role-specific interventions
4. **Transfer knowledge** from global to local context



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Thank you

