



STRM - SEND the Right Message
Registered Charity 1193572

Social Determinants of health inequalities for neurodivergent children and families

by STRM – SEND the Right
Message Registered Charity

Here we look at some of the social determinants of health inequalities for neurodivergent children and their families

Improving early identification and early intervention may prevent problems developing later in life



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Our journey

In 2019, Maggie Cleary, co-founder and CEO of STRM, established the charity after years of struggling to source appropriate support for her neurodivergent child. Finding it difficult to navigate a convoluted system, it was clear that there were additional barriers when trying to access a diagnosis or find a school who were willing and able to make reasonable adjustments, to name but a few.

Maggie felt incredibly isolated and alone, not knowing where to turn or even where to start. Along this journey, she found like-minded parents and formed our charity.

STRM – SEND the Right Message Registered Charity formed as a constituted charity on 17th February 2021.

These objectives are pursued through support services and several activities, some of which are funded by fundraising, but the bulk of which is made possible through the generosity of charitable trusts, companies, and individuals.

STRM Charity provide support services and training for families living in Southend, Castle Point and Rochford districts where there is a child who has been identified or suspected as having specific educational needs and/ or disabilities. Our support services promote personal independence and learning, while offering practical and emotional support. This can empower families to make informed choices which consider the best interests of their child or young person.

Our approach seeks to validate families and create a space for them to be seen and heard. By validating their experiences, we show that we truly understand our families' feelings and points of view as we have often been there ourselves.

STRM offers online support, face-to-face support, Disability Benefit appointments, children's activities, and training directly via our new community office.

As a charity, STRM value diversity and are whole-heartedly committed to embedding equitable and inclusive practices into all aspects of our work. We will deliberately use the term equity now, instead of equality, because we have seen first-hand how equal treatment often puts our children and colleagues at a substantial disadvantage, doing very little to foster meaningful inclusivity.

We believe that in championing equity, we are saying that, to meet people's needs, they may need to be treated differently and that is ok. We should be able to see human diversity and value those differences: true inclusivity evolves from acceptance of difference, not solely awareness of it.

Early identification and early intervention can help children and young people to develop the skills they need to live happy, healthy and successful lives. It can improve the quality of children's home lives and family relationships, increase educational attainment, improving self-esteem and reducing the incidence of clinically diagnosed mental health problems in adult life.

What are the facts?

90% of disabilities are invisible

5% of the population are dyspraxic

1-2% of the population are autistic

5% of the population have ADHD

5% of the population have an acquired brain injury

1-2% of the population have tourettes

7% of the population have mental health needs

10% of the population are dyslexic

Disabilities may be cognitive, developmental, intellectual, mental, physical, sensory, or a combination of multiple factors.

Some examples of common disabilities:

Vision Impairment
Deaf or hard of hearing
Mental health conditions
Intellectual disability
Acquired brain injury
Physical disability

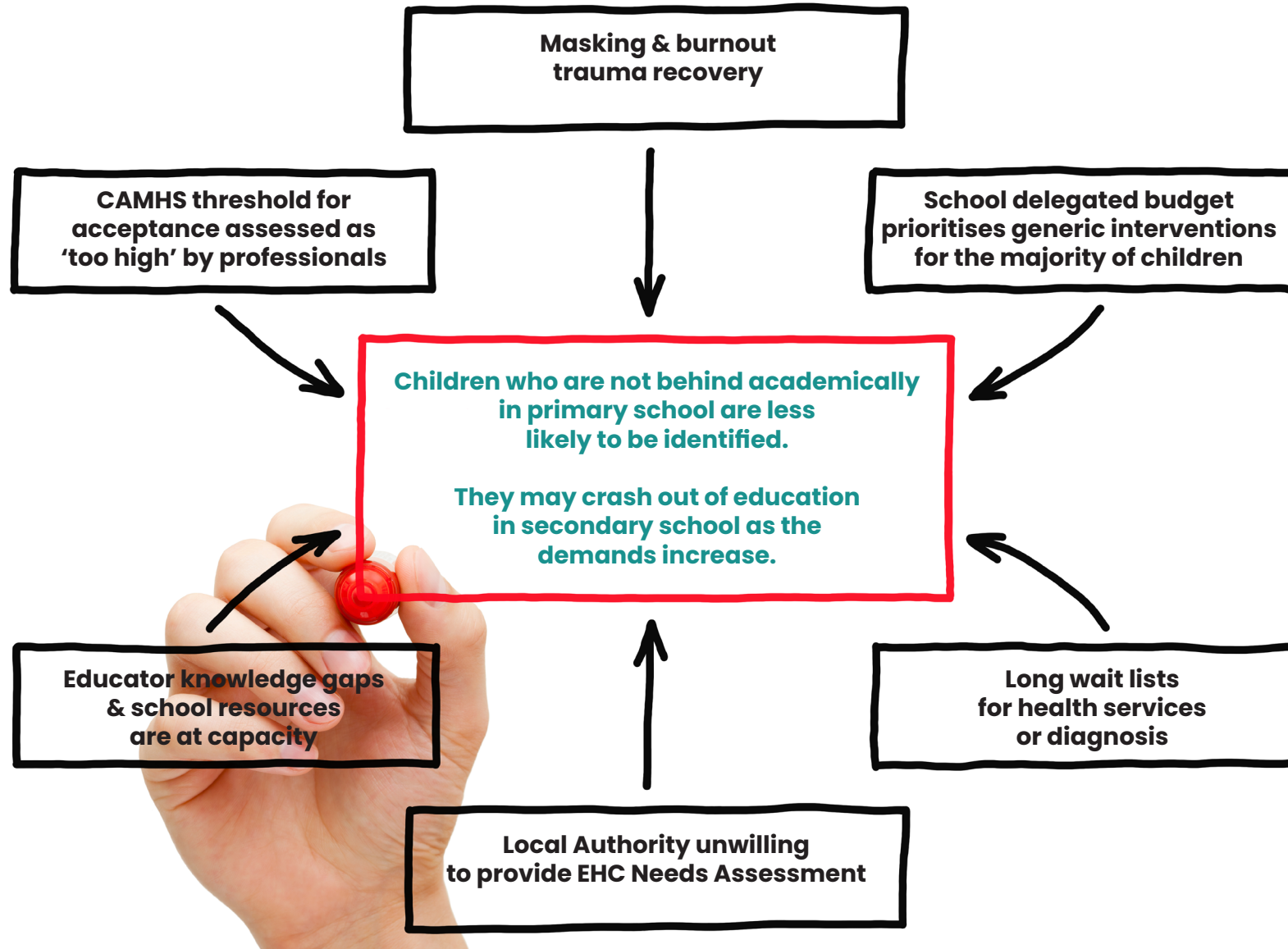
Some examples of hidden disabilities which are under the umbrella term of neurodiversity:

ADHD
Dyslexia
Tourettes
Autism
Dysgraphia
Dyscalculia

Some examples of co-occurring conditions:

Anxiety
Depression
Suicide Ideation
OCD
Eating Disorders (Arfid, PICA)
Demand avoidance anxiety

Why do neurodivergent children end up in adult mental health services?



Neurodiversity & Mental Health

What are the risks?

Up to 66% of autistic adults have thought about taking their own life

35% have attempted to take their own life

Analysis of 372 suicides indicated that a significant number were likely undiagnosed autistic

Studies show that on average, neurodivergent people are at significant risk of premature death, compared to their neurotypical peers. Autistic people in particular are more likely to die 16-20 years earlier than the average population; whilst the direct cause is unclear the studies show that autistic people are at increased risk of taking their own life, and are more likely to experience barriers when trying to access health care.

Neurodivergent Life Experiences

**Increased risk
of living with debt
or poverty**

Addiction & substance misuse are common in people with undiagnosed ND conditions

Habitual masking of neurodivergent traits to fit in with peers

Research shows that prolonged masking is linked to an increase in mental health difficulties

**Increased
difficulty
making
friends and/or
maintaining
friendships**

Likely to grow up in a household where at least one parent has an undiagnosed ND condition

Poor educational attainment resulting in poorer career opportunities

People with undiagnosed ADHD are over-represented in the Criminal Justice System

**More likely
to experience
bullying by peers**

Pressure to maintain educational attainment at the cost of their mental health

Increased risk of either perpetrating or experiencing domestic abuse

Increased vulnerability to exploitation

The effect of POVERTY

Three in ten of the **13 million people** with disabilities in the UK live in poverty: 3.8 million adults and 300,000 children.*

By contrast, the poverty rate among the non-disabled population is 20%, and this gap has persisted over recent years.

Poverty is particularly high amongst families where there is both an adult and a child who is disabled, with **4 in 10** trapped in poverty; twice the rate of families where there is no disability.

In addition to this, a further **3 million** non-disabled people who are in poverty live in a household where someone is disabled. This means that overall, nearly half of the **14 million people** in poverty are affected by disability in some way.

The report highlighted disabled people are five times more likely to be at risk of food insecurity.

It stresses that the underlying reason disabled people needed this support was simple: the income they were receiving – primarily from social security – was not enough to cover their basic needs or provide the stability they needed to improve their situation.

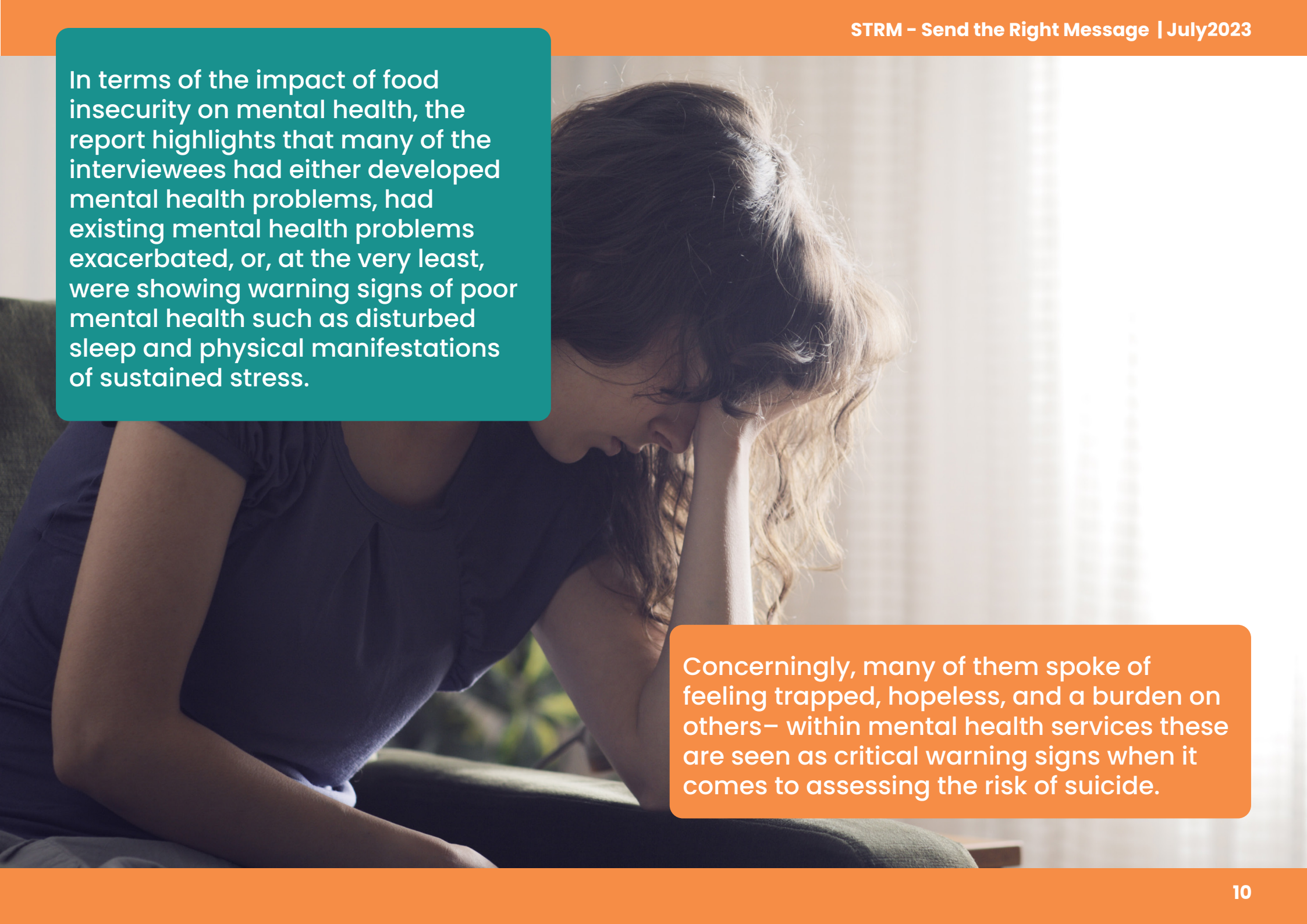
New research, co-produced by the Independent Food Aid Network (IFAN) and the Joseph Rowntree Foundation (JRF), explores the impact of poverty and food bank use on people's mental health.

More than **six in ten (62%)** families referred to food banks in early 2020 were disabled.

Disability often comes with additional costs, such as heating, insurance, equipment and therapies. These costs can dramatically reduce what disabled people have left to cover other costs, putting them at greater risk of hardship.

On average, disabled households (with at least one disabled adult or child) need an **additional £975 a month** to have the same standard of living as non-disabled households.





In terms of the impact of food insecurity on mental health, the report highlights that many of the interviewees had either developed mental health problems, had existing mental health problems exacerbated, or, at the very least, were showing warning signs of poor mental health such as disturbed sleep and physical manifestations of sustained stress.

Concerningly, many of them spoke of feeling trapped, hopeless, and a burden on others— within mental health services these are seen as critical warning signs when it comes to assessing the risk of suicide.

Employment & Education

Around half of disabled people aged 16 to 64 years (53.5%) in the UK were in employment compared with around 8 in 10 (81.6%) for non-disabled people (July to September 2021); disabled people with severe or specific learning difficulties, autism and mental illness had the lowest employment rates.

One-quarter (24.9%) of disabled people aged 21 to 64 years in the UK had a degree as their highest qualification compared with 42.7% of non-disabled people; 13.3% of disabled people had no qualifications compared with 4.6% of non-disabled people (year ending June 2021).

Housing

Nearly **1 in 4 (24.9%)** disabled people aged 16 to 64 years in the UK rented social housing compared with fewer than **1 in 10 (7.9%)** non-disabled people; they were also less likely to own their own home (**39.7%**) and less likely to live with parents (**16.4%**) than non-disabled people (53.3% and 19.2% respectively) (year ending June 2021).

Wellbeing

Disabled people aged 16 to 64 years had poorer ratings than non-disabled people on all four personal well-being measures; average anxiety levels were higher for disabled people at **4.6 out of 10**, compared with 3.0 out of 10 for non-disabled people (year ending June 2021).

The risk for disabled victims of domestic abuse

For a disabled adult, the abuse they experience is often directly linked to their disabilities and perpetrated by the individuals they are most dependent upon for care, such as intimate partners or family members who may be acting as a carer. It is also interesting to note that there is a high proportion of abuse in education settings and care homes.

Data shows that disabled victims are much more likely to be suffering abuse from a current partner than non-disabled victims (**37% vs 28%**) and over a third (**31%**) were likely to be living with the perpetrator of abuse compared to 18% for non-disabled victims.

Key Statistics on Disability and Domestic Abuse

In 2016, the Office for National Statistics published a report on Intimate Personal Violence and Partner Abuse. It found that: **16% of women** with a long-term illness or disability had experienced domestic abuse compared to 6.8% of non-disabled women. **8% of men** with a long-term illness or disability had experienced domestic abuse compared to 3.2% of non-disabled men.

Victims with a disability were more likely to experience other effects as a result of their abuse, including mental or emotional problems, difficulty in other relationships and attempted suicide.



Why might neurodivergent people develop addictions?

People can develop an addiction if they are struggling to cope with everyday life, have a particular difficulty in their lives or have a family history/ live with others with addiction.

Some neurodivergent people might also use, or even become reliant on, alcohol or drugs to mask their neurodivergent characteristics, to 'fit in'.

Misusing alcohol or drugs showed that the main reasons for this could be described as self-medicating against life's negative experiences.

Frequent and prolonged use of alcohol and drugs in this way can lead neurodivergent people to becoming addicted.

Other reasons that neurodivergent people may develop an addiction include:

- the need for routine and repetitiveness
- lack of suitable support and services
- to help manage emotions
- a late diagnosis of Autism, ADHD and co-occurring conditions resulting in a lack of understanding, support and unmet need
- co-occurring physical and mental health conditions
- psychological trauma, such as bereavement or abuse
- social distance from their community such as isolation and loneliness



Practical steps and the value of better services

- Providing and offering parents or carers a valuable respite from caring responsibilities.
- Debunk myths and discrimination of Mild, Moderate and Severe needs and use "case by case" basis without stigma.
- Additional investment in children's community nursing and therapy services is required.
- Statutory support services for parents should recognise their skills and expertise, rather than using a 'parent deficit model', which assumes that they are failing.
- Recognise that raising a disabled or neurodivergent child can be challenging for many parents and additional support should be offered, as needed.
- Support groups and local charities should be encouraged, supported financially and promoted. Family support models which best meet needs of neurodivergent and disabled families.

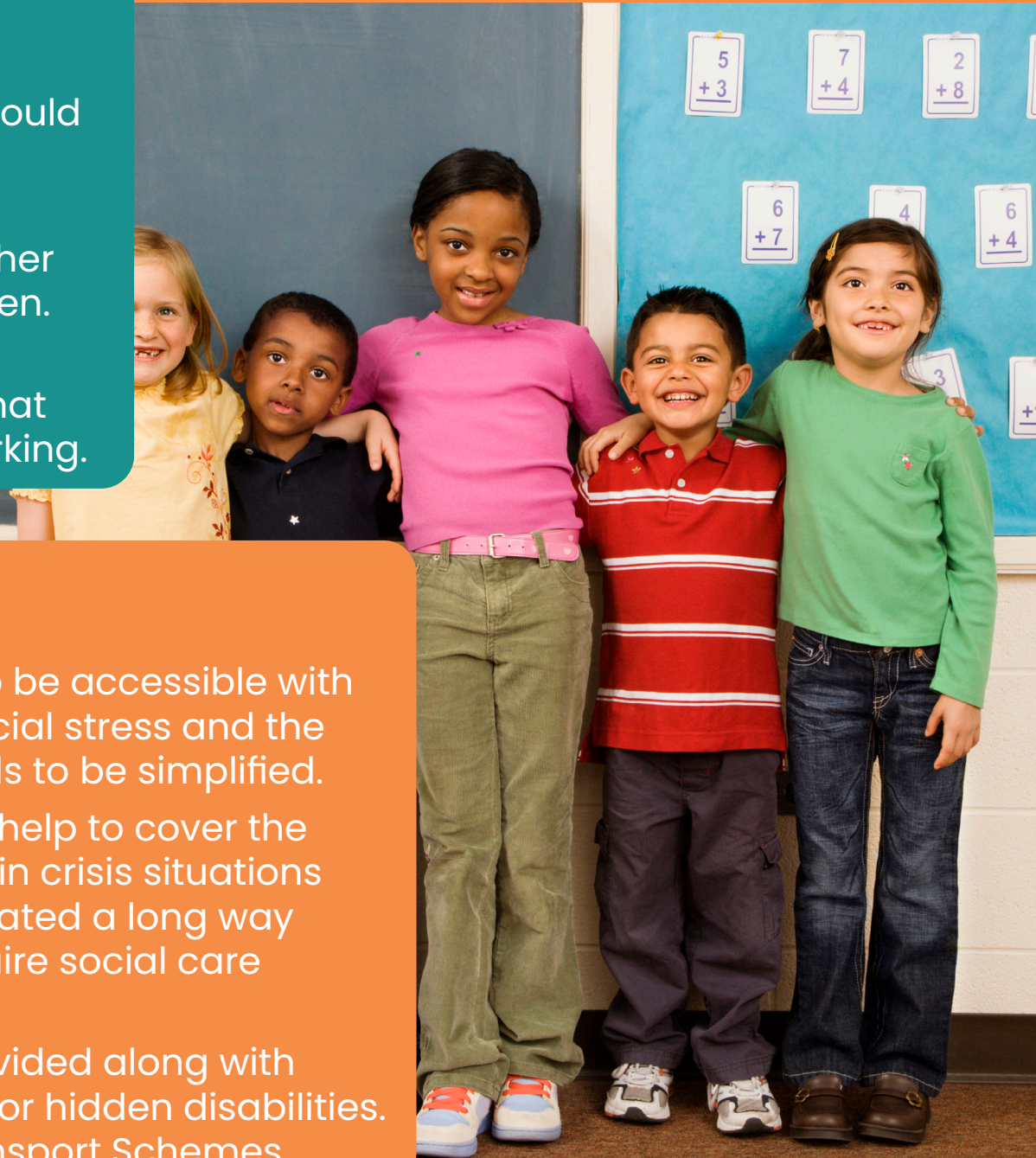


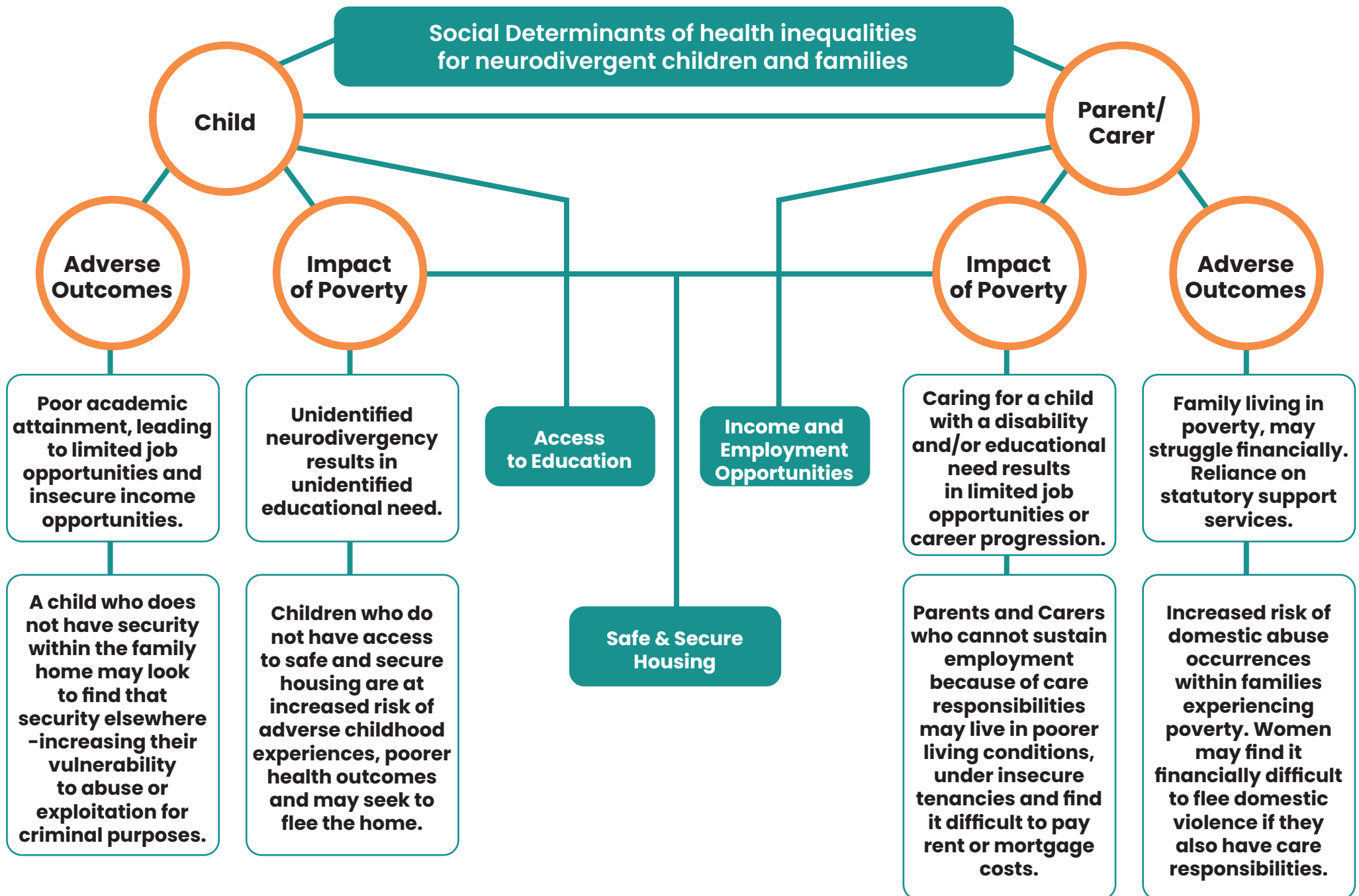
Supporting parents in work

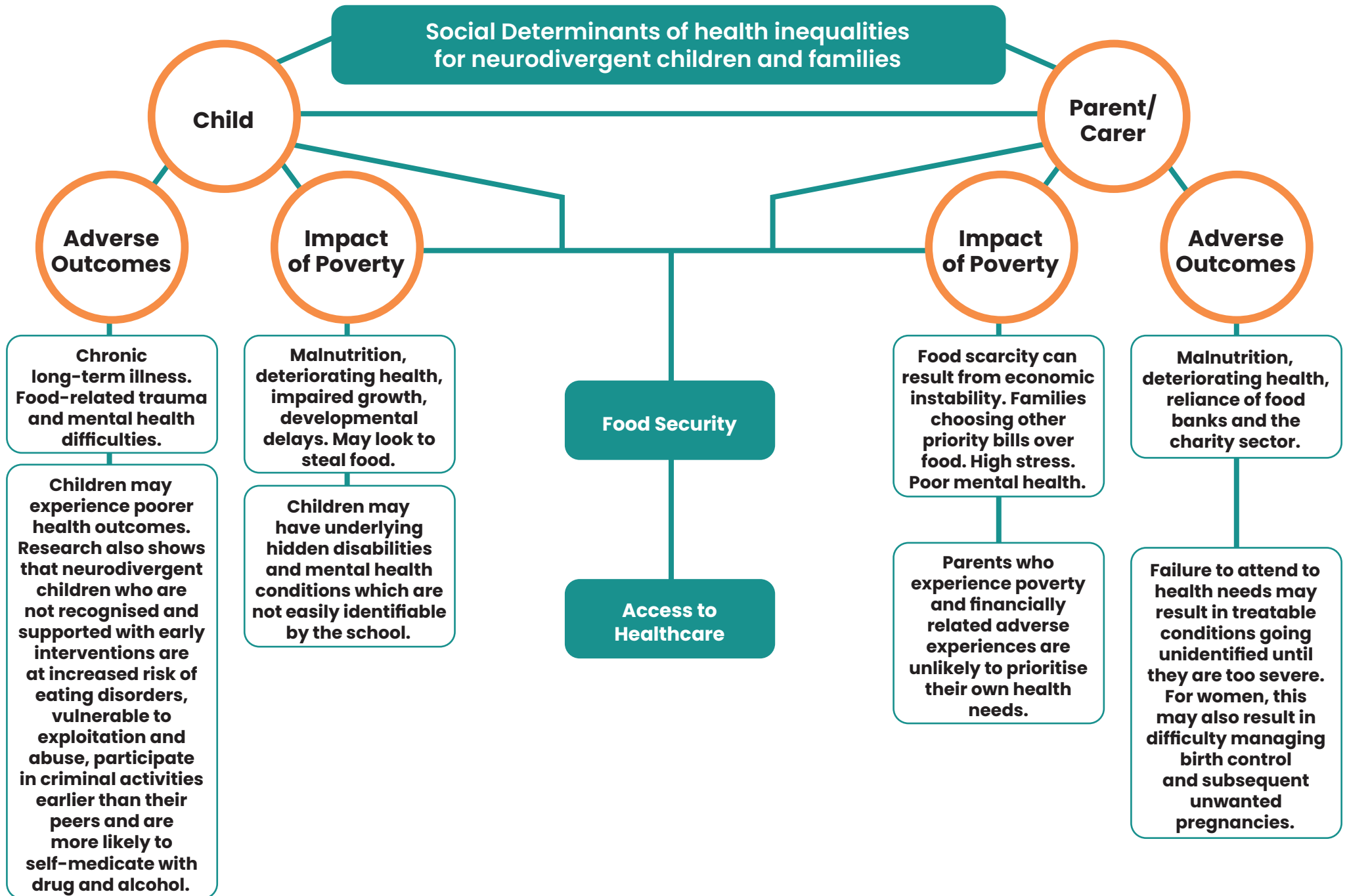
- The Government and Local Authorities should invest in suitable, affordable and flexible childcare for disabled children.
- Tax credits should include additional, higher provision for childcare for disabled children.
- Housing Benefit should be available for mortgage payments as well as rent, so that parents are never made worse off by working.

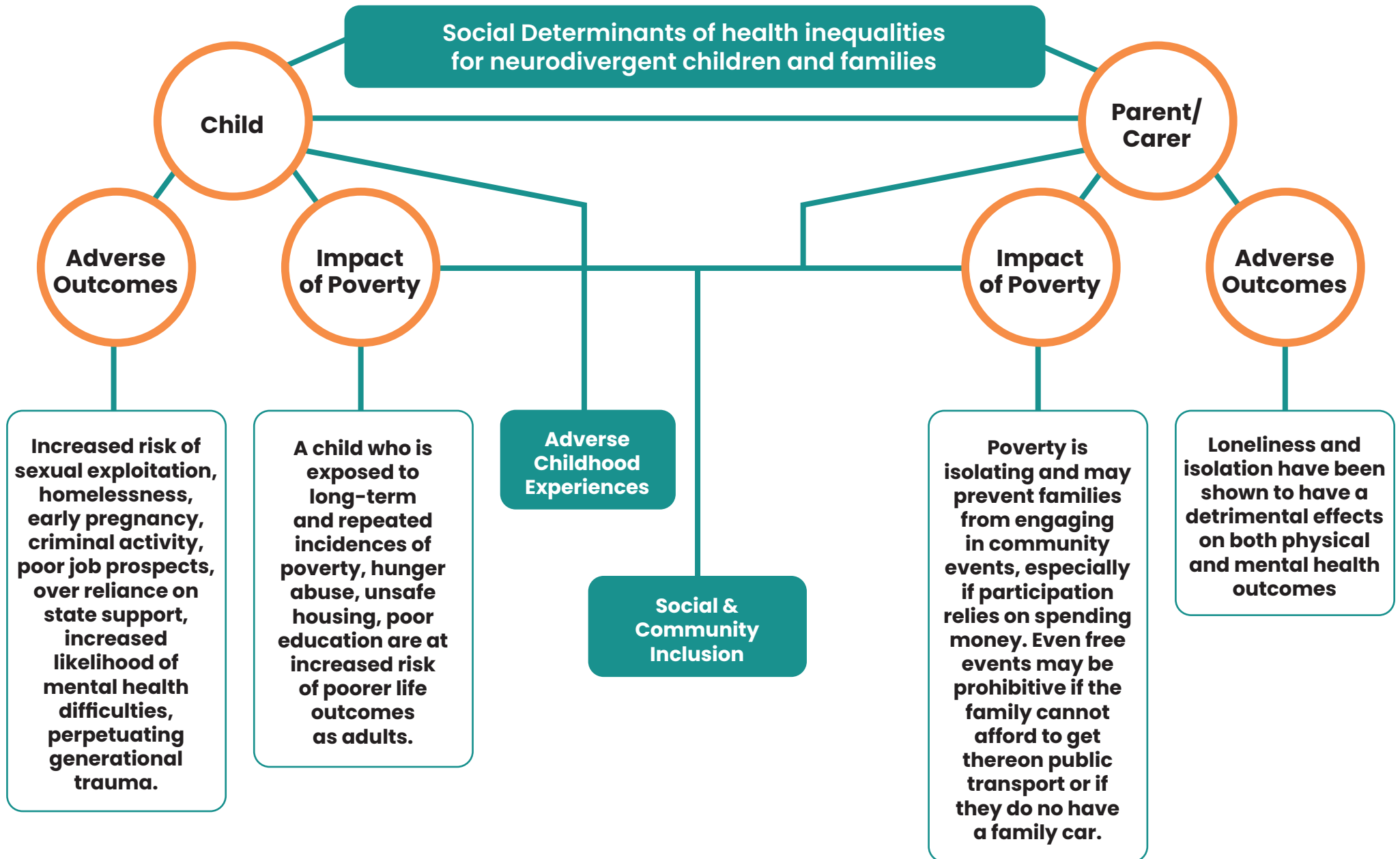
Tackling family poverty

- Disability Living Allowance, need to be accessible with support in order to minimise financial stress and the process for claiming benefits needs to be simplified.
- Families should be given financial help to cover the cost of visiting children in hospital in crisis situations particularly now that many are treated a long way from home, without having to require social care assessments.
- Blue Badge support should be provided along with eliminating discrimination locally for hidden disabilities. More information on Disabled Transport Schemes.









Credits and research

Citation

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