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Better Health, Better Lives: Research Priorities



Supporting the

*European Declaration on Children and Young People with
Intellectual Disabilities and their Families*

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ABSTRACT

Across Europe, children with intellectual disability experience broad ranging and pervasive inequalities in their health and in their life experiences and opportunities. These inequalities are, to a large extent, avoidable and unjust. This paper relates to the priority areas identified in the *European Declaration on Children and Young People with Intellectual Disabilities and their Families*.

One of the challenges facing this field is the lack of knowledge and the absence of evidence for interventions. This gap can become an excuse for inaction, even if a will to change exists. This paper serves an important purpose by outlining the present situation, and indicating a way forward. For each area the authors (1) briefly summarize the state of existing evidence that would support action in relation to the priority area; and (2) identify three priorities for further research.

Keywords

CHILD WELFARE
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ADOLESCENT HEALTH SERVICES - organization and administration
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Foreword

The International Association for the Scientific Study of Intellectual Disabilities (IASSID) is an international group of experts from all over the world, specializing in intellectual disability. We welcome the WHO's European Declaration on Children and Young People with Intellectual Disabilities and their Families, 'Better Health, Better Lives'.

We acknowledge the improvements in the lives of many young people with intellectual disabilities in a variety of countries in Europe over the last few decades. There has been particular progress made in some countries in closing institutions (for adults as well as for children), in improving access and integration for children and young people with intellectual disabilities into society, in fighting abuse and harm to children and young people with intellectual disabilities, and in recognizing the rights of individuals with intellectual disabilities. Nevertheless there is certainly still a long way to go and the ten priority areas specified in the report (protecting children and young people from harm and abuse; enabling children to grow up with families in the community; transferring care from institutions into the community; identifying individual needs; ensuring good quality health care; safeguarding the health and well-being of carers; enabling children to have a voice; building the capacity of the workforce; collecting information and assuring quality; and investing equitably) remind us of the tasks still to be achieved in order to provide children and young people with intellectual disabilities with the kinds of lives they deserve.

In *Better Health, Better Lives*, the representatives of the Ministers of Health of Member States in the WHO Region have undertaken to identify areas for intervention in their own countries and have pledged to take active steps to ensuring progress in the 10 priority areas. In order to do this, it is essential that they are well-informed of what the best available research evidence says about the lives of children and young people with intellectual disabilities, and how to improve their lives. There is a considerable amount of evidence about the ways in which the lives of children and young people with intellectual disabilities falls short of the standards that others expect for their own lives and a growing body of evidence about precisely what works in trying to bring about improvements in their lives. This document provides a brief and very timely summary of this research evidence and it delineates the research priorities, within the 10 targeted areas. It has been assembled by members of IASSID for the express purpose of providing guidance to those who will be implementing policy developments over the next few years.

We hope the summary of current evidence and suggestions for research priorities will prove helpful to all those Ministers and their colleagues in striving for better health and better lives for children and young people with intellectual disabilities across Europe.



President, IASSID

Introduction

Across Europe, children with intellectual disability experience broad ranging and pervasive inequalities in their health and in their life experiences and opportunities. These inequalities are, to a large extent, avoidable and unjust.

IASSID, as the leading international association of researchers active in the area of intellectual and developmental disability, very much welcomes the actions contained in the proposed *European Declaration on Children and Young People with Intellectual Disabilities and their Families* (Better Health, Better Lives). We also very much welcome the emphasis on evidence-based interventions and policies taken by the World Health Organization.

To support this process, the Executive Committee and Council of IASSID have developed this paper through a process of consultation with active researchers across and beyond Europe. The following ten sections relate to the priority areas identified in the proposed *European Declaration on Children and Young People with Intellectual Disabilities and their Families*. For each area we have: (1) very briefly summarized the state of existing evidence that would support action in relation to the priority area; and (2) identified three priorities for further research.

While the focus of the present document (and the Declaration itself) is on the health of *children* with intellectual disability, it is important to keep in mind that the impact of improving child health spreads far beyond the well-being of children themselves. Good child health provides a foundation for positive health, well-being and productivity in adulthood and in old age.¹⁻⁶ Good child health also contributes to the well-being of parents, siblings and other relatives.

Priority 1: Protect children and young people with intellectual disabilities from harm and abuse

State of existing evidence base to support action

There is extensive and growing evidence that exposure to ‘toxic’ levels of adversity in childhood can have a significant negative impact on children’s developmental health and well-being, and on the person’s health, well-being and mortality across the lifecourse.⁷⁻¹⁴ Evidence also suggests that, when compared to their non-disabled peers, children with intellectual disabilities are: (1) more likely to be exposed to adverse socioeconomic circumstances, bullying and abuse;¹⁵⁻²¹ and (2) as (if not more) likely to suffer negative consequences arising from such exposure.^{22, 23} There is some very limited evidence that behavioural skill-based interventions may help reduce the risk of individuals with intellectual disabilities becoming the victims of abuse or bullying.^{20, 21}

There are also threats to growth and development posed by *in utero* and early postnatal exposures to a variety of environmental pollutants and contaminants. These include heavy metals, persistent organic pollutants, tobacco smoke, and thousands of chemical compounds produced or used industrially. Many are ubiquitous in the environment. Toxicological and toxicogenetic profiles are available on only a small number of potential environmental pollutants and contaminants. Children living in poverty are at a higher risk for such exposures that can lead to intellectual disabilities.²⁴ Moreover, children with intellectual disabilities may be more vulnerable to adverse health effects from exposure to environmental toxicants than their non-disabled counterparts.²⁵

Key research priorities

Effective and ethical approaches to social and environmental protection must involve two distinct strategies: (1) prevention or reduction of the risk of exposure of children with intellectual disability and their families to adversity; and (2) increasing the resilience of children with intellectual disability and their families if exposure cannot be prevented.²⁶ Suggested research priorities are:

1. Evaluate the effectiveness of existing social protection policies (including generic policies) in reducing the risk of exposure of children with intellectual disability and their families to socioeconomic adversity, bullying and abuse.
2. Develop, implement and evaluate the effectiveness of skill-based behaviour change interventions for children with intellectual disability to reduce the risk that they will become the victims of abuse or bullying.^{20, 21}
3. Develop, implement and evaluate the effectiveness of interventions to help children with intellectual disability and their families be more resilient in the face of unavoidable adversity.^{27, 28}

Priority 2: Enable children and young people to grow up in a family Environment

State of existing evidence base to support action

The move to a community model of care as described in Priority 2 has resulted in family caregiving for almost all children with disabilities. When birth families are unable to provide a satisfactory level of care, foster and adoptive families often do so successfully.^{29,30} An extensive research base indicates that most families adapt well to their children with disabilities and are able to implement the accommodations that are necessary for satisfactory child development in multiple areas of functioning.^{28,31-39} Moreover, although parents are appropriately viewed as the primary caregivers for children with disabilities, the impact on siblings and the role of siblings during childhood and beyond has been of increasing recent interest.⁴⁰⁻⁴³ Despite the frequently successful adaptations of parents and other family members, there is still considerable variation in the degree of healthy adjustment in the course of this adaptation process. A great deal is unknown about the origins of that variance.⁴⁴

Key research priorities

1. Identification of the child, parent, and family level factors that influence the adjustment process and their variation by family type (e.g., biological parents and adoptive/fostering parents), country and culture.⁴⁵
2. Increase in the use of longitudinal methodologies to enhance our understanding of the life course implications of disability in biological and non-biological families.⁴⁶
3. Encourage research that focuses on family members (fathers, siblings, grandparents, etc.) individually as well as the family as a system in order to understand the full impact of disability.⁴⁷

Priority 3: Transfer care from institutions to the community

State of existing evidence base to support action

There is extensive evidence from high income countries that the move from more to less institutional settings is associated with an overall improvement in the quality of life for adults with intellectual disability.⁴⁸⁻⁵² This evidence also indicates, however, that: (1) benefits are more notable in some domains of quality of life (e.g., meaningful engagement) than others (e.g., mental health and behavioural outcomes); (2) the nature of institutions and their replacement services varies widely across jurisdictions; (3) there is significant variation in the quality of life of people with intellectual disabilities in more inclusive and less institutional services.⁴⁸⁻⁵² There is also strong evidence that severe institutional deprivation in early childhood can have persistent adverse effects on children's development.^{53, 54} There is little research that contrasts the quality of life for adults with intellectual disability who continue to live in the family home compared to those who move to supported community settings elsewhere.

Key research priorities

1. Country and culturally specific research to identify factors (in the child, their pre and post institutional experience and support) that are associated with more positive outcomes of deinstitutionalization.⁵⁵
2. Country specific research on the costs and benefits of alternative community residential placements, including the impact of deinstitutionalization.
3. Country and culturally specific research to identify factors associated with families choosing institutional/residential care for a child with intellectual disability.⁵⁶⁻⁵⁸

Priority 4: Identify the needs of each child and young person

State of existing evidence base to support action

There is extensive evidence from high income countries that the identification of children with intellectual disability and provision of interventions appropriate to their needs results in better developmental outcomes, at least in the short to medium term.⁵⁹⁻⁷¹ There is also good evidence to support targeting interventions to the specific needs of children and young people with intellectual disability and their families to alter children's and young people's developmental trajectories and prevent secondary complications.⁷²⁻⁷⁶ There is evidence from high, middle and low income countries that attitudes and beliefs about intellectual disability result in exclusion of children and young people with intellectual disability from mainstream health, education and welfare programs such that their health status, learning ability and quality of life is significantly diminished.^{47, 77, 78}

Key research priorities

1. Country and culturally specific research to develop robust screening methods for maternal and child health services, preschools and schools to identify infants, preschoolers and school entry age children with intellectual disability
2. Country specific research to identify specific cultural barriers that prevent children and young people with intellectual disability from accessing general health, education and social welfare systems and to identify the best methods to ensure that infants and young children with intellectual disability are referred to and enrolled in early intervention and health care services, preschools and schools.
3. Development, implementation and evaluation of the effectiveness of early intervention and transition programmes for children with intellectual disabilities.

Priority 5: Ensure That Good Quality Mental And Physical Health Care Is Coordinated And Sustained

State of existing evidence base to support action

Although less evidence is available than in relation to adults, children and young people with disabilities in general are subject to considerable inequalities in health. When compared with their non-disabled peers, children and young people with intellectual disabilities are at increased risk of developing emotional, behavioural and mental health problems that affect typically developing young people and young people with disabilities alike.^{23,79} Severe and unusual “challenging behaviours” that place young people and carers at risk of exclusion and abusive treatment and that may be more uniquely characteristic for individuals with intellectual disability are also prevalent.^{80,81} Children and young people with intellectual disabilities are also at increased risk of physical health problems including problems with serious long-term health consequences such as obesity.⁸²⁻⁸⁴ Research evidence suggests that these health inequalities emerge early in children’s development, certainly by age 5 years.^{82,85} Research addressing access to services is less well developed, and does not always indicate poorer access to support.⁸⁶ Intervention research is also lacking, although some promising data suggest some success with tools aimed at increasing awareness of health concerns among health care providers and empowering adolescents with intellectual disability and their caregivers to advocate for health.⁸⁷

Key research priorities

Interventions and models for services are needed that address these health inequalities. At least three components are important: (1) reducing barriers of access to mental and physical health care experienced by children and young people with intellectual disabilities especially by linking together different services (e.g., health, social care, education) and across the transition from pre-school to school, (2) increasing the skills and knowledge available in services, and (3) evidence based interventions either adapted from models successful with typically developing children and young people and/or interventions developed for these children and young people. Suggested research priorities are:

1. Develop an evidence base for interventions and models of services that reduce barriers of access and increase knowledge and capacity in services to improve physical and mental well-being in children and young people with intellectual disability.
2. Develop, implement and evaluate the effectiveness of biomedical and psychosocial interventions to improve health and emotional well-being in children and young people with intellectual disability.
3. Develop, and evaluate models for the wide dissemination of this evidence that can be used to empower children and young people, their families, carers, and advocates, and to contribute to sustainable and coordinated services with positive outcomes for children and young people with intellectual disability.

Priority 6: Safeguard the Health and Well-Being of Family Carers

State of existing evidence base to support action

There is strong evidence that the mothers (and to a lesser extent fathers) of children with intellectual disability are at increased risk of poor physical and mental health when compared to parents of typically developing children.⁸⁸⁻⁹⁷ However, the strength of this association appears to vary by culture, socioeconomic conditions and a range of parent (e.g., coping strategies, psychological acceptance, hope, parenting style) and child characteristics.⁹⁷⁻¹¹³ In particular, it appears that poorer health outcomes are primarily associated with the child's behavioural problems and the socioeconomic context of parenting, rather than the child's intellectual disability *per se*.^{90, 104, 107, 110, 113-118} A range of interventions and supports (e.g., knowledge focused training and standard service models including case management, cognitive behavioural group interventions and parent-led support networks) have been shown to have a positive impact on parental well-being.¹¹⁹⁻¹²³

KEY RESEARCH PRIORITIES

The development of better social protection of the health of family carers requires descriptive or epidemiological approaches to determine the extent of adverse impact, as well as interventions to reduce such impact and promote positive well-being. Suggested research priorities are:

1. Conduct country and culturally specific research on the impact of caring for a child with intellectual disability on family carer physical and psychological well-being.
2. Develop, implement and evaluate the impact on family carers of interventions to reduce challenging behaviours in children with intellectual disability.
3. Develop, implement and systematically evaluate which aspects of family supports (e.g., respite, income supplements, parent/carer training) will exert the greatest positive impact on carer physical and psychological well-being.

Priority 7: Empower Children and Young People with Intellectual Disabilities to Contribute to Decision-Making about Their Lives

State of existing evidence base to support action

Self-determination, which can be described as “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life”,¹²⁴ has been associated with a variety of positive outcomes for children and young adults with intellectual disabilities. These benefits include better employment outcomes;^{125, 126} greater access to general education instructional settings;¹²⁷ improved physical and psychological well-being;¹²⁸ and greater independence.¹²⁹⁻¹³² Despite these benefits youth and young adults with disabilities typically are less self-determined than their non-disabled peers with fewer opportunities to make choices in their daily lives.¹³³ Key factors facilitating self-determination include 1) attainment of skills such as (a) self-management, (b) choice/decision-making, and (c) problem-solving; 2) provision of supports and assistance allowing the individual to control events (e.g, through self-advocacy and social capital); and 3) opportunities to act upon the environment through social inclusion and an enriched environment.¹³⁴

KEY RESEARCH PRIORITIES

1. Develop and evaluate the effectiveness of interventions to promote self –determination that take into account such moderating variables as culture, gender, age, level of intelligence, and level of adaptive skills.¹³⁵
2. Examine the impact of social-environmental variables (range of supports, technology, and enhanced opportunities) on self-determination and quality of life.
3. Examine the role of self-determination across the life span, including factors facilitating the development of skills in early childhood¹³⁰ and in secondary education.¹³⁶⁻¹³⁸

Priority 8: Build Workforce Capacity and Commitment

State of existing evidence base to support action

Through childhood and young adulthood, the workforce supporting children with intellectual disabilities and their families will be extremely diverse. Although the research is somewhat inconsistent, several factors appear to be associated with improved competence amongst this workforce. For teachers and other education professionals, these factors include knowledge of intervention techniques, self-efficacy in the intervention approaches used¹³⁹ and the ability to work with a range of other professionals.^{140, 141} For professionals supporting families, families consistently report wanting respectful, collaborative and consistent long-term relationships with reliable, knowledgeable and ‘human’ professionals to ensure the maintenance of a collaborative and productive relationship over time^{142, 143} – these views concerning preferred characteristics are largely shared by family support professionals.¹⁴⁴ Policy shifts in some countries towards families having greater control over their support are likely to have profound effects on the workforce supporting children and families, although our understanding of these impacts is limited.¹⁴⁵

Research concerning both specialist intellectual disability professionals and mainstream professionals suggests that professional attitudes and beliefs can be quite negative about the effectiveness of working with children and young people with intellectual disabilities in mainstream settings,¹⁴⁶⁻¹⁴⁸ and that these attitudes can significantly impact upon the effectiveness of education and other support services.^{140, 141, 149} Factors consistently associated with improved attitudes and beliefs include specialist training embedded within general professional training,¹⁵⁰ and positive vision and leadership in mainstream settings backed up by individualised support for professionals working with disabled children.^{140, 149, 151}

Research concerning stress and burnout amongst professionals working with children with intellectual disabilities and their families varies widely in terms of levels of burnout reported,¹⁵² although the factors associated with professional burnout are similar to those reported in research concerning professionals working with adults with intellectual disabilities.¹⁵³ Organizational factors such as poor working conditions, role conflict, role ambiguity and support from colleagues and supervisors appear to be particularly important in addition to factors associated with the child with intellectual disabilities, such as challenging behaviour or level of intellectual ability.^{152, 154, 155}

Key research priorities

The existing research is scattered, uneven in quality and scope, and geographically patchy. More international research is required to establish:

1. What aspects of professionals’ beliefs, attitudes and behaviours have the greatest impact on educational, social, health and economic outcomes for children with intellectual disabilities and their families?
2. What policy, systems and organizational factors have the greatest potential to develop and maintain an effective workforce in terms of positive beliefs and attitudes, positive job performance and resilience to burnout?
3. What impact will the transfer of funding to individuals or their families to purchase support (personalization) have on the workforce required to support children and families, and how can a ‘personalised’ workforce be effectively developed and maintained?

Priority 9: Collect Essential Information about Needs and Services and Assure Service Quality

State of existing evidence base to support action

Effective measurement is widely seen as an essential component of effective and efficient health and welfare systems. It is fundamental to: estimating need; describing and monitoring change in the health status of populations and groups; evaluating the impact of social policies; and establishing approaches to quality enhancement/improvement.¹⁵⁶⁻¹⁷²

Quality is a relative term and one that is viewed and defined differently by different stakeholders. As such, it is important that indicators either be chosen by consensus across stakeholder groups or, alternatively, reflect the distinct concerns of different groups.¹⁶⁶

There are significant methodological challenges associated with identifying representative populations of people with intellectual disability, understanding their specific concerns regarding health and collecting information on their health and well-being.^{159, 161} Some of these concerns are particularly relevant to collecting information from and about children with intellectual disability.¹⁷³ Very few self-report measures of health status have been validated specifically for respondents with intellectual disability, suggesting that existing self-report general health status measures should be used with caution.¹⁷⁴

Key research priorities

The existing research on measuring the health of children with intellectual disability and using this information effectively to redress the inequalities in health and well-being faced by these children is sparse. More international research is required to establish:

1. What set of indicators of the health and well-being of children with intellectual disability most accurately reflects the key concerns of stakeholders (including children with intellectual disability themselves)?
2. How can information on such indicators be most efficiently and accurately collected and disseminated?
3. Under what conditions is the collection and dissemination of information on the health and well-being of children with intellectual disability most likely to lead to improvements in health status?

Priority 10: Invest to Provide Equal Opportunities and Achieve the Best Outcomes

State of existing evidence base to support action

In many, if not all, countries, young people with intellectual disability are poorly served by existing health and welfare services.¹⁷⁵ In general, there are powerful social and economic arguments to support increased social investment in the early years of life to promote the well-being of children, and in particular groups of children whose development may be compromised.^{7-14, 61, 176-181} A small, but growing literature, has documented the social and economic benefits of increased investment in early intervention for children with or at risk of intellectual or developmental disabilities.^{59, 61, 64-71, 73, 74}

The support and care of children with intellectual (and other) disabilities are associated with increases in a range of direct and indirect costs.¹⁸²⁻¹⁹⁷ In many countries a significant proportion of these additional costs are likely to be borne by their families.

KEY RESEARCH PRIORITIES

1. Country specific research on the costs, including the informal and indirect costs to the individual and their families, associated with care for children and young people with Intellectual disability.
2. Country and culturally specific research to explore existing approaches to investment in care and interventions for children and young people with Intellectual disability with a view to identifying frameworks for assessing costs within an ethical framework that takes into account quality of care, its evidence base and equality of access.
3. Country specific research on the costs and benefits of specialized placements vs. local provision.

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